The Quality of Life of Adults with Intellectual Disabilities

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Declaration

The research described, and the preparation and composition of this thesis, is my own work, except where the contributions of others are documented and acknowledged.

Preface and Acknowledgments

The research described in this thesis was prompted by interest in the quality of life outcomes for a cohort of adults with intellectual disabilities who transferred from hospital to community-based social care in the context of the first planned closure of a learning disability hospital in Scotland. This strategic change and associated resettlement programme was implemented between 1994 and 1999 by planning partners in health, social work, housing and voluntary organisations. Having participated in this programme as a member of the planning and commissioning team, and as Clinical Director of the learning disabilities service, the opportunity to explore the impact of these service developments, and the outcomes for individuals, was of professional, as well as academic, interest.

The primary focus of the research was an investigation of the extent to which resettlement resulted in positive differences in quality of life following relocation from institutional to community care and what differences might remain in the quality of life of adults with intellectual disabilities in the community compared to that of non-disabled general public counterparts. However, the potential for adaptation and development of the World Health Organisation multi-dimensional measure of quality of life, the WHOQOL, for use with an intellectual disabilities population was of great interest also. Developed as part of an international cross-cultural collaboration and reported to reflect a universal core concept of quality of life, this measure was thought to offer considerable potential in the context of a study involving adults with intellectual disabilities as well as the general population.

The research could not have been carried out without the commitment and co-operation of the NHS, the local authorities, the housing agencies and the social care providers who were involved in the change programme and responsible for the care of the adults with intellectual disabilities who were the focus of the study. I am indebted to the many colleagues in these organisations who facilitated the study and provided access to their intellectual disability services. In particular, the financial support provided by Lothian Primary Care NHS Trust, Communities Scotland (formerly Scottish Homes) and Midlothian Council is gratefully acknowledged.

Thanks are due to Professor Mick Power, University of Edinburgh, for the stimulation, encouragement, support and advice he provided as lead supervisor of the research; and to Professor Bill Lindsay, University of Abertay, for his helpful advice as second supervisor.

Sue Anderson and Eleanor Chalmers contributed to the data collection, and their role as research assistants during parts of the project was invaluable. Eleanor Chalmers contributed to the collection of relevant literature, as did Suzanne Deas and Sheilagh Hynd for a short period; and Nicole Tait transcribed some of the focus group material and photo-reduced images for the structural equation models. Sue Anderson provided additional support by proof reading the final manuscript.

Especial thanks are due to all the adults with intellectual disabilities, their relatives and the staff who participated in the preliminary pilot work; to the adults with intellectual disabilities and their staff who took part in the main study within the hospital and community groups; and to the members of the public who participated within the comparator group. The insights I gained about quality of life from these individuals made the research an interesting and most enjoyable experience.

Finally, the research would not have been embarked upon, nor the thesis completed, without the encouragement and support of those closest to me. My greatest debt is to the two people who made the whole thing possible, by supporting my ambition at the start and then giving me the courage to stay the course.

To all of you, my warmest thanks.

Abstract

The replacement of institutional care for people with intellectual disabilities with community care and accommodation has been established social policy in many countries for a number of years. Successive studies have reported improvements on various dimensions of quality of life, immediately following community resettlement and over longer periods; however, the extent to which new service models promote lifestyles and life experiences comparable with those of the general population is less well documented.

The thesis comprises four related studies which explore aspects of the quality of life of adults with intellectual disabilities in hospital and community settings in the context of recent developments in Scottish social policy; compare the life experiences of intellectually disabled adults in NHS and social care with that of adult members of the general public; and describe the adaptation and development of an international measure of quality of life (the WHOQOL) for the intellectual disability population.

In *pilot study one*, the themes relevant for comprehensive assessment of the quality of life of adults with intellectual disabilities were generated by focus groups of clients in health and social care, staff working in this specialty, and relatives of individuals with intellectual disabilities. The findings suggested that the facets of quality of life measured by the WHOQOL were relevant to adults with intellectual disabilities also, but required to be supplemented by additional themes specific to this client group.

These findings informed *pilot study two* in which the WHOQOL-BREF (the abbreviated version of the WHOQOL-100) was customised and developed for an intellectual disability population with simplified item wording (retaining semantic equivalence), the introduction of additional items (reflecting the supplementary quality of life facets), and pictorial augmentation of item response scales; and a small field trial of the adapted WHOQOL-ID was carried out, as part of which an initial analysis of the psychometric properties of the new scale was conducted.

In a *subsidiary study*, a survey of 51 community based social care and accommodation projects for adults with intellectual disabilities was carried out; structured interviews were conducted with care staff about the suitability and effectiveness of this accommodation; and a pilot housing fit index reflecting the match between the care needs of resident clients and the characteristics of project accommodation was developed.

The findings of pilot study two underpinned refinement of the WHOQOL-ID for use in the *main study*, which employed a three level between-groups design to compare the quality of life of 204 community clients living in the social care projects described in the subsidiary study, 213 learning disability hospital residents (matched with the community group for gender, age, and dependency) immediately prior to resettlement as part of a hospital closure programme, and 208 members of the general public (matched with both groups for gender and age, and with the community group for locality). The data collected were used to carry out a full evaluation of the psychometric properties of the final instrument also.

Significant differences found between the three groups were discussed with reference to implications for social policy and service developments in intellectual disabilities; and suggestions for future research were outlined.

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List of Abbreviations

Able (Wessex Schedule)	Self-help Skills
ADL	Activities of Daily Life
CAN (Wessex Schedule)	Continent, Ambulant and No Severe Behaviour Disorder
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CHI	Community Health Index
CMH	Campaign for the Mentally Handicapped
DANIS	Dependency and Needs Information System
DDRS	Degree of Dependency Rating Scale
DHHS	Department of Health and Social Security
DPH	Director of Public Health
DX,	Hypothesised Domain X
DY, DZ	Empirically Derived Domains Y and Z
EFA	Exploratory Factor Analysis
EQS	Structural Equation Modelling Package
GP	General Practitioner
HC	Health Care
HFI	Housing Fit Index
IASSID	International Association for the Scientific Study of Intellectual Disabilities
ID	Intellectual Disabilities
ID Adult	Adult with Intellectual Disabilities
ID Client	Client with Intellectual Disabilities
ISD	Information and Statistics Division (of the National Health Service)
LEC	Life Experiences Checklist
NDG	National Development Group
NHS	National Health Service
QOL	Quality of Life
SBP (Wessex Schedule)	Severe Behaviour Problems
SC	Social Care
SHHD	Scottish Home and Health Department
SPI	Social and Physical Incapacity
SPSS	Statistical Package for Social Sciences
SSL	Speech, Self-help and Literacy
WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of Life Measure
WHOQOL Group	World Health Organisation Quality of Life Group
WHOQOL-100	Full 100 Item Version
WHOQOL-BREF	Abbreviated 26 Item Version
WHOQOL-ID	Adapted 36 Item Version for Intellectual Disabilities Population

Chapter 1

Review of Social Policy and Service Development for People with Intellectual Disabilities: Institutionalisation to Community Care

The whole earth is our hospital
Endowed by the ruined millionaire,
Wherein, if we do well, we shall
Die of absolute paternal care
That will not leave us, but prevents us everywhere.

T. S. Eliot 'East Coker', Four Quartets, Collected Poems 1909-1962

It is 1924. A young woman is admitted to a new institution - she has had an illegitimate child. She is not very bright and no one told her about sex, so she is categorised as a moral defective and certified. She is accommodated in a new villa on the estate of a former mansion house that is home to 40 women. There is a big day room, a dining room and two large dormitories. The staff wear stiff uniforms and adopt stiff standards. They are kindly, but the ward regime is strict. There are set times to get up, to eat, to work and to go to bed. There are set days to bathe and to change clothes. She is told that during the week she will work in the laundry and as a ward maid. The work will be hard and the hours long. On Sundays, she will attend a church service in the grounds. The routine is not centred on inmates, but organised for the convenience of staff. No one asks her opinion of anything, offers her choice, or assumes she understands anything. No one has any expectations of her at all. Her family will not remain in contact and she will have no visitors. Her life will be hard, monotonous, but safe. Seventy years later, someone will tell her that the institution will close and that she will move to 'the community'. And the eighty-six year old woman will cry...

Such institutions are a relatively modern phenomenon, but their growth and subsequent demise has formed the backdrop to the lives of several generations of residents, professionals and policy-makers.

Historical Perspective

Historically, people with intellectual disabilities[1] were neither segregated nor secluded (Hattersley et al, 1987, Myers and Clacher, 1987). It is likely that many such individuals either died young, or found ways of contributing to their society by performing simple duties within the context of the family and largely rural and agricultural communities. In these settings, intellectual ability was less important than the capacity to fetch water, carry out household chores, plant crops or feed animals.

[1] The term 'intellectual disabilities' is the preferred contemporary international nomenclature throughout this thesis. However, other terminology is used variously in this chapter, in the context of either historical developments or early documents and publications.

Intellectual disabilities (then termed idiocy) was largely seen as a domestic problem (Digby, 1996) and thus for centuries, people with intellectual disabilities who survived into adulthood were either cared for by their families, or relied on early forms of social welfare provided by the monasteries and, subsequently, the parish.

With the development of industrialisation in the 18th century, the requirement for participation in more skilled and less supported work made it more difficult for people with disabilities to contribute meaningfully. Many people, particularly in western society, migrated to towns and cities where earning a living equated to working in a factory, a mill or a pit (Malin et al, 1980). The pressure for profit and hence efficient production left little room for those unable to contribute to the generation of wealth. Individuals with physical or mental impairments who were unable to compete in this environment tended to become confined to the home, where some were subject to effective incarceration and others risked being cast out to fend for themselves as a drain on family resources (Hattersley et al 1987).

Attitudes began to change towards people with intellectual disabilities during the late 18th and early 19th centuries, as a result of interest in the potential for educational reform directed at enhancing the workforce and improving social behaviour; and by a growing sense of social responsibility, and a desire to set new standards of public morality, in Victorian society. In the 1830s and 1840s evidence from Europe suggested that children with intellectual disabilities might benefit from education also, and the first private schools for mental defectives were established in England in 1846, and in Scotland in 1855 (Hutton, 2000).

Around the same time, private asylums were established for the relatives of those in the Victorian establishment who could afford to pay for the care of family members with mental illness or intellectual disabilities. In contrast, poorer people who could not look after themselves, and had no relatives willing to care for them, were often simply imprisoned. The Poor Law Amendment Act of 1845 sought to remedy this social injustice by requiring parish councils either to provide places in poorhouses, or pay for places in the asylums. During the 1850s and 1860s 'subscription hospitals' supported by charitable donations were developed in various locations (e.g. Earlswood, Surrey in 1853; Starcross in Devon in 1864); and the first public authority provision, the forerunner to Darenth Park, was established in the 1870s (Jones, 1972). Similar developments took place in Scotland, with the foundation of an 'Idiot Asylum' in Edinburgh in 1855 and a National Institution for 'Imbecile Children' in 1863 (Digby, 1996). However, in 1881, a census of public institutions recorded 29,452 'idiots', and indicated that 97% were distributed between workhouses, lunatic asylums or prisons, and only 3% were receiving care in institutions specifically designed for them (Jones, 1960, 1972).

The Idiots Act of 1886 recognised a difference between mental illness and intellectual disabilities (Morris, 1969) and opened the way for (but did not require) local authorities to provide special asylums for idiots, the feebleminded or mental defectives, similar to, but separate from, existing lunatic asylums. However, when the Lunacy Act was introduced in 1890, it made no such distinction, and for many years the two populations remained accommodated and treated in the same facilities.

At the turn of the century, the interest in the role of education in improving the working capacity of the masses, accompanied by concern about social issues connected with mental deficiency, led to debate about whether the condition was amenable to education or socialisation; whether it was the product of heredity or environment; and whether the sterilisation or segregation of women and girls of child-bearing age might prevent its occurrence in future generations. This debate was fuelled by the impact of the science of genetics and the eugenics movement. The work of Galton on inheritance, of Cattell and Binet on the development of intelligence testing and classification, and the conclusions drawn from early heredity studies, for example those of Dugdale (1910) and Goddard (1912, 1914), influenced public concern about perceived links between mental deficiency and a range of problems including crime, alcoholism, anti-social behaviour and illegitimacy (Jones, 1960; Morris, 1969). The prevailing view of mental deficiency began to crystallise and it was seen as hereditary, insusceptible to treatment and training, and a growing danger to the whole of society (Jones 1960).

The Royal Commission on the Care of the Feeble-minded was established in 1904 to consider these issues. At the conclusion of its deliberations in 1908, it recommended to parliament the need for protection of people with mental impairments, ascertainment, certification, detention and segregation, but did not endorse sterilization[2]. One of the members of the Royal Commission, Tredgold (whose *Textbook of Mental Deficiency* was first published in 1908) believed that the only way society could protect itself from the burden of social ills associated with mental deficiency was through segregation to prevent propagation. This view was influential in the drafting of the 1913 Mental Deficiency Act (Malin et al, 1980), which incorporated the recommendations of the Royal Commission and gave statutory recognition to the distinction between mental illness and mental deficiency.

The 1913 Mental Deficiency Act defined four categories of mental deficiency comprising idiots (greatest intellectual disability), imbeciles (intermediate level of intellectual disability), feeble-minded (least intellectual disability), and moral defectives (those with a range of intellectual disabilities and various types of immoral, anti-social or criminal tendencies); established District Boards of Control as regulatory authorities with responsibilities for their protection and

[2] Contemporaneously in 1907, Indiana was the first of fifteen states in the USA to pass laws providing for mandatory sterilisation of groups (including idiots and imbeciles) considered to be biologically undesirable (Digby, 1996).

supervision; provided for institutions for people with mental deficiency to be developed separate from asylums for the treatment of people with mental illness; and set out fairly wide conditions under which children or adults with mental deficiency could be sent to these institutions or placed under guardianship (e.g. at the insistence of a parent, if incapable of receiving education, if found without visible means of support, or if guilty of a criminal offence). The intention of the 1913 Act was to provide a social solution to what was perceived as a social problem (Jones, 1972) and the association of mental deficiency with a medical model of care was yet to emerge.

Development of Institutions

When the Mental Deficiency Act came into force on 1st April 1913 (a seemingly inauspicious date), there were 2,163 people with mental deficiency receiving care and treatment in institutions established as a result of the Idiots Act. By the end of that year a further 796 beds had been provided (Jones, 1960); however, the First World War delayed the building of many new institutions until the 1920s. Subsequently, large segregated institutions or 'colonies' were developed in many areas, sometimes on the outskirts of centres of population, but often in remote settings. Members of the Boards of Control discharged their supervisory functions by making regular inspection visits to institutions. For example, on 26th December 1924, a member of the Scottish General Board of Control wrote the first Visiting Commissioners Report on the first purpose-built institution[3] in Scotland:

> *...this institution, which is the germ of a larger and wider scheme for the education and care of the mentally defective, will ripen into a satisfactory, efficient and economical means of solving the complex problems associated with mental deficiency in the community...*[4]

This optimism remained for some years and the size of institutions grew steadily. On 27 April 1948 the Visiting Commissioner's Report noted:

> *...useful and interesting occupation is provided in the gardens and grounds, the workshops, laundry, kitchen, sewing room and the wards...willows for basket making are grown in the grounds...there are 73 children on the school roll, the majority of whom are educable...the others trainable...*[5]

However, while segregation of people with mental deficiency continued to be regarded as an effective means of dealing with perceived social problems, it was turning out to be a costly solution as numbers increased; and the institutions took on the character of places of detention rather than care (Jones, 1960).

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[3] Identified as 'Hospital A' in Chapter 4 of this study.
[4] Source: Hospital Archives
[5] Source: Hospital Archives

In July 1948, the National Health Service was established. Institutions for people with intellectual disabilities became hospitals incorporated under the direction of Regional Hospital Boards, and local authorities were given permissive (but not mandatory) powers for 'prevention, care and after-care of illness and mental defectiveness' (section 28, NHS Act 1946). By 1950 the numbers in hospital had risen to around 57,000 (Morris, 1969) and by 1954 people with mental illness and/or intellectual disabilities occupied 42% of the NHS bed complement. However, in its first five years of operation, only 16% of the NHS budget had been spent on these groups (Jones 1972). There was serious overcrowding in many hospitals; much of the accommodation was considered unsuitable for the modern forms of treatment; and the stigmatising and depersonalising nature of the institutional services provided in hospitals was beginning to be recognised. It gradually became apparent that institutionalisation fostered isolation, which in turn maintained and exaggerated the difference between people with intellectual disabilities and mainstream society, and thus sustained their continuing confinement. As Digby (1996) noted, even in the late 20th century, one in three patients never received visitors, and three out of four never left the hospital to visit their families.

Jones (1972) argues that the early 1950s were 'revolutionary' years in relation to the confluence of three trends that would shape future services for people with intellectual disabilities. First, tranquilliser drugs, notably the chlorpromazine group developed in 1952, had a calming effect on patients (without them losing consciousness) and relieved, or at least stabilised, many disturbing symptoms, introducing the possibility of pharmacological control rather than physical control by staff. Second, the beginnings of the 'open-door' movement, and the forging of closer links between hospital and community services, provided opportunities for some patients to return home with follow-up care provided in the community, and allowed others to avoid admission and receive alternative care. Third, the government set up a Royal Commission to enquire into the legal framework of care for those with mental illness and mental deficiency, which culminated in the Mental Health Act of 1959.

The report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (1954-1957) advocated two major lines of reform: first, that people with mental deficiency should be entitled to the personal social services available to the general population; and second, that hospital care should be provided only for those requiring specialist treatment or full-time nursing supervision. It recommended that local authorities should develop parallel community care services and that the numbers of places in hospitals should be reduced significantly. At around the same time, a Joint Expert Committee of the World Health Organisation published guidelines on legislation in the field of mental deficiency which focussed on the need for appropriate levels of protection (avoiding over protection), safeguards against compulsory detention (to be used as a last resort only), and requirements for supervision of the institutions (Malin et al, 1980).

The 1959 Mental Health Act (1960 in Scotland) made it possible for people with mental illness or intellectual disabilities (then termed mental subnormality) to be admitted to hospital informally, thereby reducing the social stigma attached to formal certification; and it became the statutory duty of local authorities to provide a range of alternative social services for people with intellectual disabilities, including residential care. Although some individuals would still need to be detained in hospital either in their own best interests, or for the protection of others, the notion of compulsory detention (and thus virtual imprisonment) as a *requirement* ceased to be a barrier to treatment (Morris, 1969).

Following the implementation of the 1959 Mental Health Act, many people in mental subnormality hospitals had their status reviewed and became informal patients, and the rate of admission to institutions stabilised (Morris, 1969). However, only a small proportion of people with intellectual disabilities transferred to non-institutional care, as lack of resources (both financial and staffing) delayed the development of alternative services, and many institutions relied on the cheap (or sometimes non-paid) labour of more able residents who contributed to work in the wards, kitchens, laundry, grounds and associated farms or small-holdings (Hattersley et at, 1987).

By 1965 the average number of occupied beds remained at approximately 57,800; and the average weekly cost of maintaining a patient in a mental subnormality hospital was less than all other patient groups, and even lower than average prison costs (Morris, 1969).

Essentially, the status quo of hospital as the main alternative to care within the family home remained, despite the best intentions of the legislators. However, a growing body of research on the potential of people with intellectual disabilities began to challenge the assumptions of the institutional system; and finally, the major shortcomings of the system were exposed, as the overcrowding, poor conditions and harsh treatment regimes became the subject of public scandal.

Early Psychological and Sociological Research

Experience in the institutions had shown that many people with intellectual disabilities could be taught the simple skills required to work within the framework of the organisation. In the absence of alternatives to hospital care, research interest at this time focussed on the extent to which level of intellectual functioning was 'fixed' (Clark and Clark, 1953, 1954; Clark and Hermelin, 1955); the potential for enhancing capacity to work through rehabilitation training (Tizard and O'Connor, 1952; O'Connor and Tizard, 1956); the effect of the environment on performance (Clark et al, 1958); and the impact of social competence training (Gunzburg, 1960, 1961, 1968).

The findings of studies from the 1950s undoubtedly advanced understanding of intellectual disabilities and improved the lot of many individuals, albeit mainly those termed 'high-grade', but was constrained by the framework of the existing service structure and the predominantly medical model of care. However, throughout the 1960s and 1970s, a series of studies had reported the impact of alternative services and models of care in producing superior developmental gains in the context of small, well-staffed, residential units (e.g. Tizard, 1964); the high proportion of people who did not require the specialised medical and nursing services associated with hospital care (Leck et al, 1967; McKeown and Teruel, 1970); that around two thirds of adults in mental handicap hospital were continent, ambulant and had no severe behaviour disorders (Kushlick and Cox, 1967; Kushlick, 1968); and suggested that at least half of those in such hospitals could be accommodated in the community if adequate supervision and suitable occupation or training facilities were provided (e.g. Browne et al, 1971).

In the context of this expanding research, it is arguable which studies shaped a different pattern of service developments. However, one strand of seminal work may be exemplified by Morris' sociological survey of mental handicap hospitals. In *Put Away*, Morris (1969), reported highly critical findings from a study of the quality of institutional provision[6] for people with intellectual disabilities. She found physical conditions to be 'dilapidated and decrepit'; over one third of patients slept in dormitories with 60 or more beds; privacy was non-existent; few patients had individualised clothing or personal possessions; average staff to patient ratios were low at 1:16; there was little consensus amongst staff about the objectives of care; and treatment programmes were found to be 'uniform' and not geared to individual need.

A series of influential studies (e.g. King and Raynes, 1968; King, Raynes and Tizard, 1971), which were more empirically based, reached similar conclusions and identified several inter-related characteristics of the pattern of hospital care: rigidity of daily and weekly routine, unlinked to the needs or preferences of residents; group or 'block' treatment of residents with the inevitable consequence of each person spending considerable time awaiting 'their turn', for example to be bathed or toileted; depersonalisation (for example in the sharing of clothing) and lack of opportunity for individuality or privacy; and social distance between staff and residents, reflected in a lack of social relationships and interactions typically confined to the delivery of instructions and reprimands.

In conjunction with the work of Goffman (1961, 1970) on the effect of 'total institutions' (in which the normal separation of places to live, work, and enjoy leisure activities is violated; and there is a barrier to departure), in producing a syndrome of 'institutionalisation', depersonalisation and social apathy, these studies were a powerful indictment of the hospital system.

[6] From a sample of 34 Hospitals in England and Wales

Scandal and Public Enquires

Thus far, the debate on the care and treatment of people with intellectual disabilities had been confined largely to professional circles. However, in the same year that *Put Away* (Morris, 1969) appeared, Cortazzi (1969) selected another chillingly accurate title, *The Bottom of the Barrel*, for a paper on similar themes, and the sensational report[7] of the enquiry into allegations of cruelty and neglect at Ely Hospital was published.

Ely was a former Poor Law institution with approximately 600 patients, about three-quarters of whom had intellectual disabilities. In 1967, a nursing assistant made various allegations to a national newspaper concerning ill-treatment and lack of care of patients, and pilfering of patients' property by staff. The enquiry substantiated these allegations; drew attention to failures of management, ineffective administration, lack of supervision of standards, poor staff training, low staff morale, weak medical leadership and an inadequate complaints system; and criticised those responsible at every level from ward staff to the Regional Hospital Board.

Similar enquiries into conditions in other mental handicap and psychiatric hospitals followed (Farley, 1971; Whittingham, 1972; South Ockenden, 1974; Normansfield, 1979). The failings of hospital regimes were exposed to the full glare of national publicity (Malin et al, 1980) and finally public and political concern was initiated. Although the precise nature of the allegations and complaints differed in each case, taken together the enquiries highlighted the effects of geographical remoteness, social and professional isolation; the low expectations of custodial regimes; the dangers of corruption in closed societies; the lengths to which staff and management would go to stifle and subvert criticism of patient care; the continuing lack of resources for services for these groups of patients; and the weakness of the overall system of management in its failure to monitor or influence care practice and quality (Martin, 1984).

Policy Reform and Service Development

Following the Ely scandal, professional and public concern about the problem of mental handicap hospitals led to a review of social policy in England and Wales, in the form of the White Paper *Better Services for the Mentally Handicapped* (DHSS, 1971). The well intentioned aims of the document were to: 'explain why the present services need to be extended and improved, and the shift in emphasis from care in hospital to care in the community accelerated; invite greater sympathy and tolerance on the part of the public for the mentally handicapped in their own communities, and to stress the importance of the help

[7] Report of the Committee of Enquiry into Allegations of Ill-Treatment of Patients and Other Irregularities at the Ely Hospital Cardiff (1969). The Howe Report (Cmnd 3795) HMSO, London.

they can give through voluntary services; give local authorities and hospital authorities guidance on the lines on which the government wish their services to develop; and describe the programmes of improvement and development that have been started, and what needs to be done' (paragraph 3).

Whilst recommending almost a fifty percent reduction in hospital beds and a commensurate growth in community social care places, little guidance was given on the type of alternative provision required, or the process of transferring institutionalised patients from hospital to community care. The document was underpinned by the assumptions that more able individuals would become the responsibility of the local authorities; those with more severe disabilities would remain in hospital care; and the residual hospitals would become smaller, more modern and provide co-ordinated therapeutic services. Almost inevitably, *Better Services* was criticised from all quarters, being too extreme for the traditionalists and too conservative for the radicals (Malin et al, 1980); and as it was advisory only, it produced little noticeable shift in the balance of residential provision (Jones, 1975).

Despite accumulating evidence from de-institutionalisation programmes elsewhere (e.g. Nebraska's programme of community housing) which were influential in shaping thinking in the 1970s (Digby, 1996), programmes based on medically led institutional models of care remained predominant through the 1970s. During this period resettlement initiatives were typically intermittent, incremental and often targeted towards the most able hospital residents i.e. those without complex needs or significant behaviour problems (Emerson et al, 1994). As a result, the characteristics of the resident population in many hospitals began to shift towards higher dependency, more serious challenging behaviours and more complex patterns of disabilities, all of which placed an increasingly heavy burden on staff, which in turn, may have contributed to the punitive and controlling nature of the regimes highlighted by public enquiries.

In the early 1970s, the burgeoning normalisation movement, which was formulated in Scandinavia, became a rallying cry for those seeking service reform in both the USA and the UK. The ideology was a reaction to the empirical findings on the impact of institutionalisation, and advocated that services based on normalisation principles should provide conditions of everyday life as close as possible to that of mainstream society; elicit (or maintain) culturally normative behaviour using culturally normative methods and practices; and maximise the quality of life of people with intellectual disabilities by promoting the lifestyles and range of experiences valued by non-disabled individuals (Bank-Mikkelson, 1969; Nirje, 1970, 1976; Gunzburg and Gunzburg, 1973; Wolfensberger, 1972). The proponents of normalisation maintained that institutional models of care emphasised the negative, and devalued, qualities of people with intellectual disabilities, and argued that new services should seek to promote dignity, individuality and social value (Wolfensberger, 1972; O'Brien and Tyne, 1981).

These aspirational principles were operationalised and expressed as five objectives that were promulgated widely as the criteria by which the achievements of services, and the accomplishments of service users, might be evaluated: community presence; relationships; choice; competence; and respect (O'Brien, 1987).

In the UK, the newly formed Campaign for the Mentally Handicapped called for the closure of all hospital provision and its replacement with community services based on ordinary models of housing (CMH 1970, 1972). This lobbying group was influenced by the philosophy of normalisation and by national and international research demonstrating the superiority of community services (Ericsson and Mansell, 1996). Partly in response to this, the National Development Group (NDG) was established in 1975 to further develop policy; and in 1976 the associated Development Team was formed to stimulate the modernisation of services. The Group produced a series of publications setting out ideas on planning and developing services, which were influential in professional circles at the time, but against the background of economic recession and public sector spending constraints, little change took place (Malin et al, 1980).

Acceleration of Resettlement and Development of Community Care

In the early 1980s, policy development in England and Wales diverged. In the wake of the Ely enquiry, the hospital had been refurbished at considerable expense (Martin, 1984). The criticism that this attracted led to the setting up of NIMROD, a community service demonstration project in Cardiff (Welsh Office, 1978). The outcomes from this project stimulated the formulation of a national 'All Wales Strategy' to provide earmarked and ring-fenced resources for development of a pattern of community services that would enable institutions to close entirely (Welsh Office, 1982, 1983).

In England, the Jay Report[8] emphasised the rights of people with intellectual disabilities to be treated as individuals and recommended an ordinary housing model of care as the way forward for services (Digby, 1996). Following this, the Department of Health funded a research and development project in Andover (Felce, 1989); and a subsequent national demonstration project gave recognition to the *eventual* goal of de-institutionalisation in England by establishing eleven centrally funded 'Care in the Community' initiatives (e.g. Davies and Challis, 1986; Knapp et al, 1992; Cambridge et al, 1994). These led the way for the first full hospital closure programmes, involving two of the largest and longest established institutions in England, Darenth Park in Kent (see Korman and Glennerster, 1985) and Starcross in Devon.

[8] Report of the Committee of Enquiry into Mental Handicap Nursing and Care (1979). HMSO, London

At the end of the decade the White Paper *Caring for People* (DHSS, 1989) and the subsequent NHS and Community Care Act 1990 set out the organisational principles and financial basis for the continued development of community care. For people with intellectual disabilities the key policy aspects were: development of packages of care based on assessed individual need; development of a mixed economy of care drawing on a range of providers and based in small units; local authority social services departments taking lead responsibility for assessment and care package design; and the NHS having responsibility for the organisation and delivery of health care in the community, but providing beds only for those with clear medical or nursing needs.

Scottish Policy and Service Development

In Scotland, the pace of development of community care was much slower (Emerson and Hatton, 1994).

The underlying principles of a shift in the balance of residential provision from hospital to community set out in the 1971 White Paper *Better Services for the Mentally Handicapped* (England and Wales), formed the basis for a joint policy statement *Services for the Mentally Handicapped* issued by the Scottish Home and Health Department and Scottish Education Department in 1972.

Thereafter, against the background of the scandals and public enquiries in England and Wales, a review of progress achieved since 1972 was published as the Peters' Report, *A Better Life* in 1979. The report found considerable regional variation in the community services that had been developed; and concluded that there remained a national shortfall in provision, partly as a result of economic constraints that had prevented further expansion of community facilities. The 1972 policy statement (known colloquially as the 'Blue Book') had recommended that 1.6 residential places (1.2 hospital beds and 0.43 community residential places) per 1,000 population were required for people with intellectual disabilities in Scotland. Based on updated prevalence studies and population projections for Scotland, the Peters' Report modified this target by raising the total requirement to 1.8 places, and recommending a split of 1.2 hospital places and 0.6 community places. The creation of a 'national service for the mentally handicapped' was considered and rejected; closer co-operation and co-ordination between statutory agencies and voluntary organisations in planning services was encouraged; conditional joint financing arrangements were recommended to stimulate progress in the development of community-based care, with priority accorded to residential accommodation; but hospital provision remained endorsed, as 'an essential part of a comprehensive service... for the foreseeable future' (paragraph 7.23).

On a number of occasions over the years, Scotland had gone its own way in terms of the direction of policy or the pace of developments[9], but on the brink of the 1980s, the Peters' Report seemed to fly in the face of both the prevailing ideology and the evidence of positive outcomes emerging from alternative service developments elsewhere:

> *'It has been suggested in recent years that the provision of hospitals for the severely mentally handicapped is an outmoded policy, which is singularly inappropriate to the needs of such persons. In our view, however, many severely mentally handicapped persons are in need of protection from the community; the protective secure life of the hospital represents for them a suitable pattern of care...' (Paragraph 7.24)*

This complacent and rather paternalistic attitude is hard to understand, although it may be relevant that there have been no formal public enquiries into the conditions in Scottish hospitals for people with intellectual disabilities. However, the Mental Welfare Commission for Scotland used its statutory powers to bring to the attention of the Secretary of State for Scotland its major concerns about the conditions and regimes in two learning disability hospitals in the mid 1980s (Report of the Mental Welfare Commission for Scotland, 1985 and 1986). Iironically, these were the same two hospitals[10] that the Peters' Report had identified in 1979 for specific prioritisation of the development of new in-patient facilities.

Following this, the *Balance of Care* study (Baker and Urquhart, 1987) set out to investigate the administrative prevalence of adults with intellectual disabilities in Scotland (i.e. of those known to, and in receipt of, services), to describe their characteristics, abilities and problems; to examine the balance of care between residential and day services, and between health and social care providers; and to determine the potential for future service change. The findings stimulated a new phase of community care development, by suggesting that more than 90% of hospital residents would be capable of living in the community if suitable accommodation and adequate support were provided; and that the full range of characteristics, skills and problems were represented in all sectors of care i.e. that even for the most dependent person in hospital, with the most complex needs, there was a counterpart in an existing community service.

However, in the period between 1980 and 1991, the hospital population declined by 51% in England, 41% in Wales and 32% in Northern Ireland, but the decrease in Scotland was only 24% (Emerson and Hatton, 1996).

In 1992, a Scottish Home and Health Department working group reviewed the role of hospitals in providing future specialist services for people with intellectual disabilities. The subsequent report (SHHD, 1992) endorsed the view that the majority of people with intellectual disabilities should receive

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[9] For example, following the Mental Deficiency Act of 1913, England pursued full institutional separation by taking those with mental deficiency out of poor law establishments into separate asylums and colonies, but Scotland continued to maintain overlapping systems (Digby, 1996).

[10] Lennox Castle Hospital and the Royal Scottish National Hospital (paragraph 7.43).

community-based services; recommended that 'large institutions should have no place in the future planning of services' (p.75); and suggested that the specialist services required to meet the needs of those with serious behaviour problems, dual diagnosis (specifically intellectual disabilities and major mental illness), or profound and complex intellectual disabilities requiring nursing care should be provided in small units, close to the communities they served.

Finally, more than twenty years after the Peters' Report (which remained extant policy guidance) a new review of services for people with intellectual disabilities *The Same as You?* (Scottish Executive, 2000) was undertaken by a range of stakeholders including policy makers, professionals, service users and their carers, and others with an interest in service development. The report identified innovative community developments and examples of good practice in various parts of the country. It drew heavily on the issue of the rights of people with intellectual disabilities to 'enjoy a decent life, as normal and full as possible'[11], and recommended that plans should be drawn up for the closure of all long-stay hospitals for people with intellectual disabilities by 2005. The report was unequivocal in the view that 'hospitals are not appropriate settings for social care, and they are not necessary settings for most healthcare' (p.6). However, it was accepted that a small number of places might be required for those requiring specialist or complex assessment or treatment, or those on statutory orders.

The Adults with Incapacity (Scotland) Act 2000 provided a structure within which decisions could be made on behalf of adults with intellectual disabilities lacking the capacity to manage their own financial affairs, or make decisions about their personal care or medical treatment; the Community Care and Health (Scotland) Act 2002 further developed a number of the policy directions set out in *The Same As You?*; and the Mental Health (Care and Treatment) (Scotland) Act 2003 set out a legal framework for alternatives to hospital admission for people requiring lengthy treatment, or longer periods within a supportive or protective environment.

In January 2004, the National Implementation Group (set up to assist the achievement of objectives set out in *The Same As You?*) published a report *Home at Last?* (Scottish Executive, 2004) on the progress achieved in the hospital closure and service reprovisioning programmes, with accompanying action points provided to assist implementation and ensure the achievement of closure targets and robust community services by 2005. The report indicated that hospital beds had declined from around 5,000 in 1990 to less than 900 in 2003; and nine hospitals of varying size had closed between 1998 and 2003.

In little more than a decade, Scotland had begun to close the gap and modernise its approach to people with intellectual disabilities.

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[11] *The Declaration on the Rights of Disabled Persons*. United Nations, 1975.

Summary

Over the years, people with intellectual disabilities have been one of a number of minority groups subjected to the vagaries of society's beliefs, anxieties, prejudices and self-interest. As Morris (1969) noted, one of the additional handicaps imposed on individuals with intellectual disabilities has been their misfortune in having a 'mistaken identity', and of being thought to be mentally ill, delinquent, anti-social, promiscuous or simply biologically inferior. The result of this confusion led to people with intellectual disabilities being seen variously as a danger to society, a social nuisance, uneducable or lacking in value to the extent that 'social euthanasia' in the form of out-of-sight and out-of-mind quarantine in institutions was regarded as an acceptable form of social welfare.

Early scientific theory and empirical work (including medical, psychological and sociological studies) both contributed to the plight of people with intellectual disabilities and helped to mediate aspects of their situation; but dogma (in the form of treatment ideology), rather than data, underpinned social policy and programmes of service development over many years.

Behind the scenes, one of the most serious problems in the story of intellectual disabilities in the UK has been the fundamental lack of prioritisation of services by politicians, professionals (except for a few champions) and the public. As Jones (1975) noted, despite everything 'nobody cares very much – at least not for very long' (p. 202); and a decade later Grifffiths (1988) described community care as 'a poor relation, everybody's distant relative, but nobody's baby'. For many years, and for a range of reasons (including stigma, prejudice, fear, ignorance, lack of empathy, low social priority and funding constraints) people with intellectual disabilities, lacking the capacity as a group to advocate for themselves, were 'airbrushed' from society and effectively disenfranchised. Systematic and systemic inertia sustained the hospitalisation of thousands of people, long after policies changed and research evidence indicated the potential for positive outcomes associated with different models of service and programmes of care.

In the last two decades, many studies have explored the impact of comprehensive de-institutionalisation programmes and the extent to which modern community-based care and accommodation has contributed to improved well-being, normalised lifestyles and enhanced quality of life for people with intellectual disabilities. Much of the early resettlement evaluation research was geared towards supporting policy advances by adding to the body of *objective* evidence for maintaining the direction of service development, particularly as the unit cost of community care increased with the transfer of individuals with higher dependency and more complex needs. However, many of these studies focused on comparisons of different service environments and models using a relatively restricted range of measures and indicators (Emerson and Hatton, 1994).

More recently, studies have explored the *subjective* experience of satisfaction with alternative services from the standpoint of the service users also, and incorporated measures of lifestyle and quality of life. However, resettlement studies that have included normative comparisons with non-intellectually disabled people, or involved other relevant reference groups such as those without prior institutional experience, are less common.

In general terms the evidence suggests that following de-institutionalisation, people with intellectual disabilities benefit from better physical and material conditions, experience more normal patterns of life, express more satisfaction with services, and have a higher quality of life. Nevertheless, a variety of institutional practices still persist in community services (Mansell and Ericsson, 1996) and many people with intellectual disabilities continue to have impoverished relationships and limited opportunities for social contacts with persons who are neither peers nor paid staff. As Digby (1996) noted:

> *Inadequate funding, stigma, social neglect, and a tendency to see those with learning disabilities as objects rather than subjects, have not immediately disappeared because the physical environment has altered. Changing the locus of care may be helpful in the longer term, in positively asserting the similarities between human beings, rather than underlining a sense of difference by physical separation. But a radically revised social construction – a reinventing of social perceptions – of those with a learning disability is also needed if fundamental improvements in lifestyle are to be permanent. (p. 18)*

Building on the foundations of earlier work, and in the context of recent developments in Scottish social policy, the current study aimed to explore the objective life experiences and subjective quality of life of adults with intellectual disabilities in both hospital and community settings and make comparisons with adult members of the general public.

A brief review of research findings from studies of the outcomes of relocation from hospital to community services is presented in Chapter 2; the background to the measurement of quality of life and the instruments that have been used with both the general population and people with intellectual disabilities is provided in Chapter 3; and the design and methodology of the current study is introduced in Chapter 4.

Chapter 2

The Impact of Service and Lifestyle Changes: Research Findings from De-institutionalisation and Community Resettlement Studies

Go, go, go, said the bird: human kind
Cannot bear very much reality.

(T. S. Eliot, 'Burnt Norton', Four Quartets, Collected Poems 1909-1962)

The first hundred years of institutional provision for people with intellectual disabilities may be summed up as an attempt to find socially acceptable and politically practical solutions to two problems: the need for social welfare and residential care for those at risk (lacking the capacity for self care); and the requirement for supervision of those perceived as presenting a threat to society (stemming from behavioural deficits, excesses or disorders). During the last fifty years, the movement to dismantle the resulting institutional structures and practices has been fuelled in equal measures by political and public shame (as the appalling conditions endured by residents of some hospitals were revealed) and by professional zeal (as evidence of the potential for more normalised lifestyles afforded by alternative patterns of care was promulgated).

De-institutionalisation (and related key research studies) in the UK may be divided roughly into three phases, the timing of which was subject to regional variation across the home countries. Phase one, typically orientated towards more able individuals, commenced in the early 1970s; phase two, which included those with more complex needs, was evident from the late 1970s and early 1980s; and phase three, geared towards the replacement of institutions with comprehensive community services, gathered pace through the mid-late 1980s and early 1990s.

Initially, the institutional exit criterion (and related resettlement qualification) was mainly competency based, and new community services were orientated to those with mild to moderate intellectual disabilities only. Rehabilitation strategies were geared to the development of adaptive behaviours and the associated reduction of maladaptive behaviours; those with the most severe challenging behaviours, mental health problems, or serious offending behaviours were deemed largely unsuitable for community care (Farmer et al, 1990); and evaluation of the success of the alternative provision was almost exclusively linked to the avoidance of hospital re-admission. The impetus generated by more radical and comprehensive change programmes e.g. the *NIMROD* service (Welsh Office, 1978) and the Andover project (Felce, 1989) finally led the way for more dependent and challenging individuals to transfer to community services in the context of more intensive support arrangements.

The de-institutionalisation process involved a set of inter-related components: prevention of new admissions by development of residential, day service and personal support alternatives to hospital care; early resettlement of individuals with the capacity to live independently (or with minimal support); promotion of rehabilitation and social education programmes to equip more dependent individuals, or groups of residents, with the skills required to function in alternative community settings; development of intensive support arrangements for those with the highest levels of need; and establishment of increased co-ordination of, and cooperation between, community based residential and day services, and between health and social services support networks.

Although preparation programmes to support individuals transferring to the community gradually became more sophisticated over the years, most remained primarily geared to community related competencies and behaviour, and less attention focussed directly on strategies for reversing the institutionalisation process, or overcoming the intra- and inter- personal adaptation that followed years of regimentation and segregation. To a large extent the staff and residents' shared burden of stigma, destruction of self-esteem and habituation to atypical patterns of social interactions (Thiele et al, 1977) were not addressed until the latter phases of de-institutionalisation. Similarly, many studies reporting on the impact of de-institutionalisation have investigated a range of features of the new services, and explored the impact of community care on the quality of life individuals with intellectual disabilities along various dimensions. However, fewer studies sought views from the service users themselves, or addressed satisfaction with life quality directly.

Service Size and Configuration

Many of the first generation of resettlement initiatives were located in large residential units e.g. the 20-24 bedded Wessex projects (Felce et al, 1980) and have been described as an intermediate model of community-based provision (Emerson et al, 1994). Subsequently, second generation community projects were smaller, typically domestic in scale, and based on ordinary housing models for groups of between two and eight (Mansell et al, 1987; Felce and Toogood, 1988; Felce, 1989). However, the changes in service and project configuration were driven as much by ideology, as reflected in influential papers such as *An Ordinary Life* (King's Fund, 1980) and *Key Concepts* (CHM, 1984), as by research findings.

Number of Residents

Some studies have suggested that larger units were associated with lower quality of care and with institutional, rather than client centred, management practices (King, Raynes and Tizard, 1971) and with less user engagement and staff interaction (Felce and Repp, 1992). Other studies have reported longer duration and higher rates of staff contacts in community houses than hospitals (Felce et al

1986); higher levels of staff contact (Mansell and Beasley, 1990) and direct assistance (Mansell and Beasley, 1993) in community houses than either hospitals or campus based units; and that smaller homes promoted higher quality interactions (Auburn and Leach, 1989; Felce, 1989; Holland and Meddis 1993) and adhered more closely to ordinary domestic models in terms of normalisation ratings (Felce and Perry, 1997). However, it has been suggested that while smaller homes may allow greater freedom and opportunities for residents, larger homes may provide the setting conditions for more relationships (Ager, 1993); and as Emerson and Hatton (1994) noted, some of the better community care outcomes have been achieved in what would be considered relatively large settings by the standards of today. Essentially, the picture that emerges is that size may be less important than the organisational structures and operational procedures of the project (the service model) and the characteristics (including ability and compatibility) of the client group.

Staffing

Adequate staffing is an essential prerequisite of high quality services, whether in hospital or the community. Some studies have reported that inadequate staffing was associated with unmet service aims and user needs in some community homes (e.g. Walker et al, 1993). However, other studies have suggested that client group size may be a more important influence on staff-client contacts (Felce, 1989; Felce et al, 1991), user engagement (Dalgleish and Mathews, 1981) and levels of client appropriate behaviour (Felce et al, 1991) than staff numbers alone or staff-client ratios; and that increases in staff have not necessarily been accompanied by similar increases in staff interaction with residents (Mansell et al, 1982; Felce et al, 1991). Community-based staff have been reported to have greater self-determination (Rawlings, 1985), be more optimistic and have greater involvement in decision-making (Murphy et al, 1991) than hospital staff; but equally it has been reported that staff in smaller community settings experience greater levels of stress (Emerson and Hatton, 1994) and have higher turnover rates (Felce, 1989).

Service Operation and Management Style

Many of the new community services were heralded as providing the normalised environments that would support de-institutionalisation, and foster more client centred care practices, and more individually tailored services, than the former institutions. Some studies have suggested little change in levels of institutional management practices in community residential settings (e.g. Emerson and Hatton, 1994); but others have reported superior management practices (Sinson, 1990), more management autonomy (Rawlings, 1985), less block treatment, depersonalisation and social distance (Hemming et al, 1981; Emerson et al, 1993), less use of shared bedrooms (Davies, 1988), increased quality of care (Stanley and Roy, 1988) and more likelihood of service users being treated as adults (Flynn, 1989), in smaller community homes compared with hospitals.

However, overall, the evidence suggests that there remains considerable variation in service operation and management style, and that some community services 'recreate' the characteristics of the institutions in microcosm (Emerson and Hatton, 1994).

Costs

As the first wave of resettlement from hospital to community settings tended to focus on individuals with the highest competence and lowest support needs, a biased and erroneous early impression of the costs of community care was created. A number of early studies reported examples of community houses where capital costs (e.g. Felce, 1981) or revenue costs (e.g. Davies, 1988; Davies et al, 1991) were lower than that of comparator hospitals. However, subsequent studies showed more mixed results, with some community placements being cheaper and some more expensive than hospital placements (Knapp et al, 1992; Beecham et al, 1997). Latterly studies have reported generally higher revenue costs associated with community services (e.g. McGill et al, 1994) and with higher dependency of service users (Shiell et al, 1992). Ultimately, it became clear that community care was far from being a cheaper option than hospital provision, particularly as unit numbers fell, and those with the most complex needs were resettled. In this context, specialised units for people with challenging behaviours have been reported to be amongst the most expensive to re-provide, with typical costs around twice that of similar hospital services (Dockrell et al, 1993). Recent projections for the costs of small community group homes and supported living arrangements for those awaiting discharge in Scotland were reported to be approximately 160% of base hospital levels (Scottish Executive, 2000), despite the increase of the associated institutional costs over time.

Various studies have examined the costs associated with particular approaches to, or varying forms of, community support for people with intellectual disabilities (Cambridge et al, 1994; Myers et al, 1997; Emerson et al, 2000). Some studies reported only weak associations between costs and quality (Cambridge et al, 1994); and others suggested that increased resources were linked with higher quality to some extent (Raynes et al, 1994). However, other studies have failed to find evidence of a link between service costs and quality (Hatton et al, 1995; Emerson et al, 2000).

User Outcomes

Studies that have reported on de-institutionalisation have explored the impact of community resettlement on service users across a range of personal, social and environmental parameters. A summary of findings in relation to some of the most commonly employed outcome measures is described below.

Social Adaptive Skills and Competencies

Skill development and growth in personal competence have long been regarded as key objectives of community services (O'Brien, 1987), and in many early evaluation studies these were the key criteria used in the evaluation of service achievements (Emerson and Hatton, 1994). The majority of studies have reported developments in personal competence and skills following transfer to the community. Inter-alia studies have found examples of increased domestic activity and household skills (Fleming and Stenfert Kroese, 1990); increased self-help and communication skills (Booth et al, 1990); general skill development (McHatton et al, 1988; Knapp et al, 1992); and overall increases in adaptive behaviours (Locker et al, 1984; Felce et al, 1986; Felce, 1989; Lowe and de Paiva, 1990; Lowe et al, 1993; Felce et al, 1994). However, a proportion of studies have reported no difference in self-help skills (Rawlings, 1985); little or no difference in adaptive behaviours (Stanley and Roy, 1988; Cullen et al, 1995); and greater improvement in basic living skills compared to social skills (Walker et al, 1993) within the new models of care. It has been suggested also that skill increase may be more likely when *in vivo* techniques are employed in pre-discharge community living skill training (Michie, et al, 1997) and where changes in setting conditions (e.g. domestic scale community houses) provide opportunities for the manifestation of already acquired skills, or those on the cusp of development (Emerson and Hatton, 1994); and that over several years, personal competence may show 'plateau' effects as initial skill gains are not supplemented once the increased opportunities provided by the new environment have been embraced (Cambridge et al, 1994).

Maladaptive and Challenging Behaviours

The second wave of resettlement included people with intellectual disabilities and more complex or specialised support needs, including those with severe challenging behaviours. Many such individuals presented management problems within former hospital settings, and were considered impossible to manage in alternative community provision until the end of the de-institutionalisation process (Wing, 1989), at which point, a number of services set up additional support teams and contingency funding arrangements (Bratt and Kirby, 1995) to underpin community services. The initial expectations for this group were mixed: with many hospital staff doubting the capacity of community services to cope with severe behavioural challenges; and many social care staff hoping that normalised environments and lifestyles would reduce maladaptive behaviours which they associated with institutional patterns of life. Therefore, reduction of maladaptive and challenging behaviours became an important indicator in the evaluation of community services (particularly while policy makers remained cautious about the need for residual hospital services). In the event, outcome studies that have reported on behavioural change have produced mixed results also. Some studies found decreases in general maladaptive behaviours (e.g. Conneally, 1992) and less exhibition of stereotopy (e.g. Rawlins, 1985); while others reported increases in maladaptive behaviours (e.g. Felce et al, 1994;

Cullen et al, 1995). Nevertheless, the evidence overall tends to suggest that there may be a reduction in minor behaviour problems, but little or no change in major challenging behaviours, following community resettlement (Martindale and Kilby, 1982; Emerson et al, 1992; Knapp et al, 1992; Emerson et al, 1993; Mansell and Beasley, 1993).

Activity and Engagement

One of the most criticised aspects of the care regimes of large hospitals for people with intellectual disabilities was the block treatment of individuals (King and Raynes, 1968; King, Raynes and Tizard, 1971) and the subsequent lack of engagement of residents in purposeful everyday activities. Unsurprisingly, active engagement became one of the most frequently used outcome measures in de-institutionalisation research (Emerson and Hatton, 1994, 1996). Once again, the evidence on the extent to which the new community based services achieved higher levels of user engagement and participation in activities varied. The majority of studies have reported greater engagement, and involvement in a wider range of activities, in community settings (Felce et al, 1985; Felce et al, 1986; Thomas et al, 1986; Felce, 1989; Allen, 1990; Mansell and Beasley, 1993; McGill et al, 1994). However, some studies have reported low levels of engagement in community homes (e.g. Bratt and Johnston, 1988) or noted variations within the same study (Mansell and Beasley, 1993). Some reports suggested that user engagement was lower in the context of larger group sizes or units (Felce, 1989; Felce and Repp, 1992), and increased both with service user ability (Felce and Perry, 1995a; Felce, 1996) and the presence of one or two staff (Felce and Repp, 1992). In this context, Emerson and Hatton (1994) have suggested that approximately half of the variation in measured engagement in purposeful activity may be accounted for by the rate of assistance provided by staff; Felce (1996) has reported that up to 82% of the variance in engagement across individuals may be accounted for by the ability of the residents and the extent and nature of staff support (e.g. provision of instructions, guidance, prompts etc.); and Jones et al (1999) found that staff training in an active support model increased the assistance received by residents, and their resultant engagement in activities.

Autonomy and Choice

The promotion of opportunities for personal autonomy and choice has been a key objective of community services also. There is some evidence to suggest that opportunity to exercise choice in regard to ordinary everyday activities has increased in community settings compared to institutions (e.g. Booth et al, 1990); but opportunities for choice and control in the matter of more substantial decisions e.g. where to live, or with whom to live, have remained more restricted (Cattermole et al, 1988; Walker et al, 1993; Emerson and Hatton, 1994; Robertson et al, 2001); and there is some evidence to suggest that people with intellectual disabilities remain more restricted in terms of decision-making autonomy than the general population (Fleming and Stenfert Kroese, 1990).

Social Relationships

Social isolation has been identified as a feature of institutional regimes (Martin, 1984), and it has been suggested that the quality of life of many individuals with intellectual disabilities is closely related their patterns of friendships and social relationships (Firth and Rapley, 1990; Clegg and Standen, 1991). Thus the promotion of social relationships has been a key tenet of normalised community services. However, whereas in large hospitals many individuals were permitted freedom of the campus, with all the opportunities this provided for social contact and social relationships (albeit mostly with peers and staff), community homes have provided smaller in-house networks and safety issues have tended to impose greater restrictions on unaccompanied social contact in the wider neighbourhood (Knapp et al, 1992). Some studies have reported an overall increase in social contacts in community settings (de Kock et al, 1988; Lowe and de Paiva, 1991). Nevertheless, the frequency of social relationships with people outside the family, the peer group or the home (i.e. not relatives, fellow residents with disabilities, or paid care staff) have been reported to be relatively low (Cattermole et al, 1988; Jahoda et al, 1990; Knapp et al, 1992; Ager et al, 2001), and some studies have suggested that people with intellectual disabilities in community settings have few real friends (McConkey et al, 1983; Walker et al, 1993).

Integration and Inclusion

Amongst the many objectives of community services was the fostering of home life within the wider context of community presence and social integration (Felce and Toogood, 1988). The majority of studies that have explored the extent of community participation have reported general increases in community activities and the use of integrated facilities (Jahoda et al, 1990; Lowe and de Paiva, 1991; Ager et al, 2001). Although some studies have reported little or no difference in the use of integrated community facilities following resettlement (Bratt and Johnston, 1988; Stanley and Roy, 1988; Dagnan et al, 1995), or that use of such resources was more common both during the daytime than in the evening, and for more able individuals (Fleming and Stenfert Kroese, 1990). Overall, studies tended to suggest that whilst residents of community houses may have some degree of increased contact with neighbours (McConkey et al, 1993), and members of the general public (Saxby et al, 1986), such contact may be relatively limited and superficial (Perry and Felce, 1994), and they may have few non-disabled friends (Malin 1982; Donegan and Potts, 1988; Donnelly et al, 1997).

Research evidence on the social acceptance and degree of inclusion of people with intellectual disabilities is more mixed. Some studies indicated that members of local communities were relatively accepting of the residents of community homes, at least once these projects became established (Emerson and Hatton, 1996); and that those working in local businesses frequented by service users (e.g. shops, cafes) showed a high degree of acceptance (Saxby et al, 1986; Felce,

1989). However, there have been reports of decreases in neighbours' willingness to provide practical assistance over time (McConkey et al, 1993), and studies which suggested that many people with intellectual disabilities living independently suffered from victimisation from non-disabled people in their local communities (Flynn, 1989).

Quality of Life and User Satisfaction

Over the years, the path of resettlement outcome evaluation moved from crude global indices (avoidance of re-admission to hospital), through more detailed objective indicators (skill development, engagement in activity), to encompass other more psycho-socially sensitive measures of quality of life. This journey reflected a shift in emphasis from measurement of success according to the standards and tenets of service developers, to assessment of satisfaction as perceived by service users themselves.

Objective Conditions of Life

The majority of studies that have evaluated material quality of life, have reported a consistent picture of the superior life conditions enjoyed by people with intellectual disabilities in community settings compared with hospitals, e.g. higher quality physical environments (Cullen et al, 1995: Ager et al, 2001), more normalised and comfortable home circumstances (Conneally et al, 1992; Donnelly et al, 1996) and more disposable income (Walker et al, 1993). However, as Emerson and Hatton (1994) have pointed out, such studies tended to have focussed on a fairly narrow range of indicators, mainly for within-group and between-settings (i.e. non-normative) comparisons.

Subjective Experience of Life

Given the physical conditions and management regimes of some of the former institutions (Morris, 1969) it might be expected that community resettlement would produce consistently superior subjective quality of life. The majority of studies have reported generally higher user satisfaction with community lifestyles (e.g. Stanley and Roy 1988; Knapp et al. 1992; Walker et al, 1993; Cullen et al, 1995); but some studies have been more equivocal (e.g. Jahoda et al, 1990; Clare and Murphy, 1993). However, as noted for objective quality of life, the range of subjective quality dimensions measured in mainstream de-institutionalisation research tends to have been relatively limited, and may not have captured the complexity of later multi-dimensional models of quality of life (e.g. Felce and Perry, 1995b). Similarly, most studies have focussed on the single comparison of former hospital and subsequent community services, rather than exploring the quality of life of people with intellectual disabilities compared with their non-disabled general public counterparts living in similar community settings.

Although there are clear methodological difficulties in relation to obtaining reliable subjective quality of life reports from those with intellectual disabilities with associated limited cognitive abilities or serious communication problems (Atkinson, 1988), some studies have produced illuminating findings. When interviewed, people living in mental handicap hospitals reported wishing to live in the community, citing complaints about the stigma of living in a hospital, lack of privacy, inflexibility of rules and routines, lack of social activities and contacts, and poor relationships between residents and staff (Cattermole et al, 1988). Residents of community houses have reported similar issues also, and Booth et al (1990) suggested that the least successful features identified by movers themselves could be summarised as 'the problems of communal living and the strains and frustration these engendered in the personal relationships of people who must involuntarily share each others' lives' (p. 96). In a twelve year follow up of those resettled from hospital to community, Forrester et al (2002) found the most frequently reported positive features of community lifestyles from the users' perspective were the living environment (own room, personal possessions), the general social setting (e.g. providing companionship) and personal independence; however, aspects of the physical context of the accommodation (e.g. problems with neighbours) and the social setting (e.g. noise, problems with fellow residents) were the most frequently cited negative features also, as were the management regime (e.g. strict routines, restrictions on freedom), boredom, bullying and loneliness.

Summary

The focus of this brief review was evidence from research carried out in the context of de-institutionalisation studies in the UK (i.e. in services comparable to those of the current study). However, there are similar findings from the international body of research (Heal et al, 1978; Pratt et al, 1980; Landesman-Dwyer, 1981; Kishi et al, 1988: Kleinberg and Galligan, 1993; Maisto and Hughes, 1995; Mansell and Ericsson, 1996; Janssen et al, 1999; Stancliffe and Keane, 2000; Stancliffe, 2001; Braddock et al, 2001; Schwartz and Rabinovitz, 2001; Young and Ashman, 2004a, 2004b). Although the picture that emerges is generally positive, the gains made tend to have been modest, have occurred soon after relocation and have not been supplemented by additional major changes over time (Lowe et al, 1993; Cullen et al, 1995; Dagnan et al, 1998); and on some dimensions there remain inconsistencies between studies, There is some evidence that devaluation and stigmatisation of people with intellectuals disabilities have not been overcome in community settings (Flynn, 1989); and it has been suggested that the new service paradigms may become associated with similarly stigmatised significance in the future (Tøssebro, 1996). However, as Cullen et al (1995) pointed out 'it is clear that no advantage is to be gained by remaining in an institution' (p.491); and as Reinders (2002) has noted, perhaps the real challenge that people with intellectual disabilities pose for us is ' not so much what we can do for them, but whether or not we want to be with them' (p.5).

In noting the considerable variation in conceptual and methodological sophistication of de-institutionalisation studies, Emerson (1985) has suggested that 'the wrong questions have been asked in the wrong way' (p. 281) such that some of the issues addressed have been of peripheral importance to both policy makers and service users. Despite this, de-institutionalisation research has both informed the direction of service development and been hugely influential in maintaining the pace of service change. However, the story is far from complete (Bruininks, 1990), the strand of research focussing on the objective and subjective quality of life of people with intellectual disabilities may be the most effective in sustaining the changes made, and avoiding the creation of mini-institutions in the community.

Chapter 3 describes the background to the conceptualisation and assessment of the quality of life of people with intellectual disabilities; and provides a brief review of the measures developed specifically for the client group.

Chapter 3

Assessment of Quality of Life: Conceptual Background, Definition and Measurement

We had the experience but missed the meaning,
And approach to the meaning restores the experience
In a different form, beyond any meaning
We can assign to happiness.

(T. S. Eliot, 'The Dry Salvages', Four Quartets, Collected Poems 1909-1962)

In evaluating the impact of de-institutionalisation, a number of researchers have demonstrated the benefits of community living on a range of objective outcome measures including material standard of living, community presence, social opportunities, adaptive behaviour and engagement in constructive activities (Emerson and Hatton, 1994; Mansell and Ericsson, 1996). However, as described in Chapter 2, relatively less attention has been paid to more the global concept of quality of life, and to individuals' subjective satisfaction with their lifestyle. Within the field of healthcare generally, Fallowfield (1990) described quality of life as the 'missing measurement'; and, in the context of intellectual disabilities, Emerson (1985) put forward the view that 'evaluation of personal satisfaction has been seriously neglected' (p.282).

Bradley (1996) suggested that so-called 'first generation' research into de-institutionalisation tended to focus on process issues (transition, change management) and immediate or short-term outcomes; while 'second generation' research began to investigate the longer-term impact of community care, and the variables within programmes which predicted high quality outcomes. Even so, Emerson and Hatton (1994) sounded a warning note in drawing attention to a more cynical interpretation: that de-institutionalisation studies had focussed on those aspects of quality of life that would be expected to show change, rather than those features less likely to be affected by simple re-location (e.g. poverty, empowerment and self determination, and close personal relationships).

Conceptual Background

As a result of what might be described as an increasing symbiosis between the social policy agenda and professional interests, the relevance of quality of life as an outcome measure in human services has become more widely accepted over the past two decades (Osborne 1990). In the field of intellectual disabilities, Schalock (2004) described the 'quality of life journey' as involving two major challenges: first, operationalising the concept of quality of life; and second, overcoming doubts that enhanced quality of life was a realistic and achievable goal for people with intellectual disabilities.

The determinants of quality of life have been subject to consideration by philosophers, poets, politicians and physicians, as well as psychologists, over many years (Fallowfield, 1990). Some of the earliest writings on quality of life have been credited to Aristotle (384-322 BC) and his concepts of 'the good life' and 'living well' (Smith, 2000). In more modern times, the range of extreme, diverse, and sometimes contradictory, assumptions about quality of life can be exemplified by the proposition of the eugenics movement in the early 20th century, that some people were so disabled that society would benefit more from their deaths than their continued lives (Koch, 2000); and by Lyndon Johnston's proposals for social welfare reforms in the 1960s, emphasising the role of civil rights, education and the alleviation of poverty in creating 'The Great Society' (Prince and Prince, 2001).

The tension between different aspects of the quality of life of the individual, and/or the well-being of society, embodied in these contrasting examples is reflected in the literature in various ways. For example, Gerson (1976) described early conceptual approaches to quality of life as either *individualist*, stressing the primacy, achievements and activities of the individual, or *transcendentalist*, giving greater weight to the social order of the wider community. He argued that both approaches were inadequate, being based on a misleading dichotomy, which failed to reflect the continuing process of negotiation about the commitment and use of resources (money, time, sentiment and skill) that takes place between individuals and society, the outcome of which defines life quality. A number of writers have put forward variants of the distinction between personal welfare, i.e. the *conditions of life* and the needs of an individual within society, and personal well-being or happiness, related to an individuals' personal *experience of life* (e.g. Rescher, 1972; Osborne, 1992); and defined quality of life in terms of these dimensions separately, or in combination (Borthwick and Duffy, 1992). Felce and Perry (1995b) took forward this conceptualisation and suggested a model of quality of life combining both life conditions and personal satisfaction, moderated by personal values, aspirations and expectations. Pursuing consensus, the International Association for the Scientific Study of Intellectual Disabilities described quality of life as a sensitising (rather than definitive) concept, and proposed a framework of nine *core ideas* about life quality including domains of well-being; inter- and intra-personal variability; personal context; life span perspective; holism; values, choices and personal control; individual perception; self image; and empowerment (IASSID, 2000).

Definitions and Dimensions

To some extent, the lack of a clear consensus about the definition of quality of life remains (Borthwick-Duffy, 1989; Farquhar, 1995). Inter-alia, life quality has been defined in terms of satisfaction, contentment, happiness, fulfilment, sense of well-being, ability to cope, the difference between hopes/expectations and present experience, acceptable living conditions, and an acceptable state of physical, mental, social and emotional health (Haas, 1999).

However, one of the most complete conceptualisations of quality of life was produced by the World Health Organisation's Quality of Life Group (WHOQOL Group 1994a), which defined quality of life as:

> *An individuals' perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features in the environment (p.43).*

This definition of quality of life broadened the focus of earlier attempts to define the concept, by including positive aspects of well-being, as well as health (illness) or disability related dimensions, in the setting of both personal values and cultural norms.

The related conceptual framework for the dimensions and components of quality of life has been subject to a variety of approaches also. Spilker (1996) indicated that the five major domains of quality of life referred to most frequently in the literature were: physical status and functional abilities; psychological status and well-being; social interactions; economic and/or vocational status and factors; and religious and/or spiritual status. As a result of their cross-cultural empirical work with healthy adults, and adults with a disease or impairment (healthcare users), the WHOQOL Group (1994a, 1994b, 1995) produced six similar core domains: physical; psychological; level of independence; social relationships; environment; and spirituality/religion/personal beliefs.

The dimensions of quality of life identified as relevant to people with intellectual disabilities have contained these core domains also, but additional dimensions have been mentioned frequently, many of which related to the disadvantaged and devalued background of many individuals within this population. For example, in a review of the conceptual and empirical literature in intellectual disabilities, Hughes et al (1995) derived a consensus list of 15 major dimensions of quality of life from the conceptual work, of which the six most frequently cited in empirical studies were: social relationships and interaction; psychological well-being and personal satisfaction; employment; self-determination, autonomy and personal choice; personal competence, community adjustment and independent living skills; and community integration. Based on the quality of life literature relating to the general population as well as to intellectual disabilities, Felce and Perry (1995b) suggested five domains: physical well-being; material well-being; social well-being; development and activity; and emotional well-being. Felce (1997) further refined this conceptualisation and proposed six domains of well-being: physical; material; social; productive; emotional; and civic. Subsequently, (Schalock (1997, 2004), has suggested eight core domains: emotional well-being; interpersonal relations; material well-being; personal development; physical well-being; self determination; social inclusion; and rights.

Objective and Subjective Perspectives

Objective indicators of quality of life *(hours slept last night, number of social contacts this week, amount of money earned per year)* are open to evaluation by both the individual concerned and others around them. Such indicators are externally verifiable, and thus data collection is relatively straightforward, even in respect of people unable to provide information directly (e.g. people with severe and profound intellectual disabilities, older adults with dementia). In contrast, subjective indicators of quality of life *(satisfaction with sleep, contentment with social supports, sufficiency of income to meet needs)* are intended to capture the individuals' own perception and subjective experience, and hence methodological difficulties[1] arise in respect of individuals unable to respond directly. It has been suggested that the subjective experience of quality of life has two components: cognitive, involving appraisal of satisfaction; and emotional, sometimes encapsulated as happiness, including appraisal of positive and negative affect (Prince and Prince, 2001).

Campbell and Rodgers (1972) reported that social or objective indicators rarely account for more than 15% of the variance in individuals' quality of life, while psychological or subjective indicators account for over 50% of the variance. This suggested that experience of life might not correspond very closely to external life conditions i.e. that although life conditions may influence a person's experience of life, they do not necessarily reflect that experience. However, Perry and Felce (1995) noted that objective measurement provided a frame of reference for the circumstances of specific groups, in comparison to the population as a whole, which could be important in assessing the quality of life of individuals lacking in experience of what might be construed as acceptable everyday minimum standards by ordinary members of society (e.g. people with intellectual disabilities).

Purely objective quality of life measures (often driven by political, professional or ideological agendas) may make assumptions about the applicability of the indicators used, and hence fail to take account of differences in what individuals' may enjoy, or regard as important, in their lives; but entirely subjective quality of life measures may pose different problems, as reports of well-being may reflect personality, disposition or temperament rather than external conditions, and relatively high satisfaction scores may mask adaptation and lowered expectations of vulnerable or disadvantaged individuals to poor objective life circumstances (Felce, 1997; Felce and Emerson, 2000). Consequently, the growing agreement about the multi-dimensional nature of quality of life has been accompanied by progressive acceptance of the importance of both objective and subjective quality of life indicators (WHOQOL Group, 1995, 1998b; Felce and Perry, 1995b; Felce, 1997; Vreeke et al, 1997; Janssen et al, 1999; Schalock, 2004).

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[1] This may explain the preponderance of objective indices in early de-institutional research and the relative lack of studies that have examined personal satisfaction.

Measurement

A variety of approaches have been taken to the integration of quality of life assessment as part of treatment and programme evaluation in the field of publicly funded health and social care: simple uni-dimensional single measures, more complex multi-dimensional single measures and multiple separate measures (Haas, 1999). This diversity has been reflected in the conceptualisation and measurement of quality of life within both general healthcare, and in specific clinical populations (Bowling, 1997b).

Quality of life was introduced as a relevant treatment outcome variable in healthcare because traditional medical measures of health status such as mortality, morbidity or disability either failed to represent adequately the range of potential outcomes of clinical interventions, or were unable to differentiate marginal differences between competing therapeutic approaches (Spilker, 1996).

Some of the initial unidimensional approaches to the measurement of health-related quality of life were relatively unsophisticated, and involved selection of a rating on a single scale. For example, one of the most frequently and widely used measures in the medical literature, the *Karnofsky Performance Index*, (cited in Fallowfield, 1990), was first devised in the 1940s as a non-physiological outcome measure in the treatment of oncology. This scale measured physical functioning and dependency only, and yielded a physician determined rating between 'normal, no complaints' (scale score of 100%), through 'disabled, requires special care and assistance' (40%), to 'dead' (zero).

Many similar early scales attempted to condense complex multi-dimensional concepts into single dimensions (focussing predominantly on functional ability related to everyday activities and work capacity) without reference to the impact of disease and disability on individuals' psychological, social, inter-personal, or environmental circumstances (Kind, 1988; Bowling, 1997b). In this respect, 'return to normal living' was assumed to approximate to satisfactory quality of life within the general health field (Schipper et al, 1996), in the same way that normalisation and community re-location was presumed to deliver satisfactory quality of life for people with intellectual disabilities.

Subsequently, broader and multi-dimensional measures of health status were developed. Typically, multi-dimensional approaches included assessment of objective components (e.g. functional ability, psychological well-being, social status) as well as subjective elements (e.g. life satisfaction, morale, self esteem) producing scores or profiles from ratings on separate scales, rather than a single aggregated score (Fletcher et al, 1992). For example, the *Nottingham Health Profile* (cited in Bowling, 1997b) was introduced in the 1980s to assess the subjective experience of ill health, and comprised 38 items across six dimensions (mobility, pain, energy, sleep, emotional reactions and social isolation), each with a range of possible scores from zero to 100.

In a review of the methodological issues related to the assessment of quality of life, Fallowfield (1990) put forward the following set of basic requirements for such measures: reliability; validity; availability of normative data; suitability for target population; simplicity and intelligibility of items and response format; avoidance of ambiguous, value embedded or socially loaded items; an appropriate balance of comprehensiveness and brevity; and application of a suitable timeframe; and suggested that:

> *Undoubtedly we still have a long way to go before a completely satisfactory, scientifically valid and acceptable measure of quality of life is developed, but ... failure to attempt to monitor quality of life is neither good medicine nor good science (p.71).*

Between 1990 and 1999, there was more than a fourfold rise in published reports of the development and evaluation of health related quality of life measures (Garratt et al, 2002). However, some researchers (e.g. Brown et al, 1996) have stressed the importance of the broader paradigm of overall quality of life (rather than the narrower construct of health related quality of life) in the evaluation of treatment and rehabilitation; and latterly instruments have been developed which extended health related dimensions to provide a measure of overall life quality, an example of which is the WHOQOL (Andresen and Myers, 2000).

An International Approach to Quality of Life

In the 1990s, the WHOQOL Group set out to devise an international measure of overall quality of life that included a broad range of domains, covering all the important aspects of quality of life, and was both reliable and valid cross-culturally. The resulting instrument, the WHOQOL-100 was developed within the context of a research collaboration across five continents and 15 countries, selected to reflect differences in industrialisation, culture, religion, health service organisation and other markers relevant to the measurement of quality of life (WHOQOL Group 1994b). The WHOQOL methodology had several unique features which included employment of a simultaneous approach to international instrument development (WHOQOL Group, 1995); use of a structured and detailed iterative process[2], which integrated contributions from researchers, health professionals, lay groups and international expert reviewers (Szabo, 1996); and application of a tested WHO translation method of repeated forward and backward translation, complemented by a review process by monolingual and bilingual groups to ensure conceptual, semantic and technical equivalence (Sartorius and Kuyken, 1994; WHOQOL Group 1994b).

There were 12 main stages of instrument development, which involved concept clarification, qualitative pilot work, developmental pilot work, and field-testing, each of which was carried out simultaneously in all participating field centres:

[2] This aspect of the WHOQOL methodology informed the development of the WHOQOL-ID within the current study.

i. An initial working definition of the quality of life concept (quoted above) was proposed, and constituent dimensions were generated and described.
ii. Focus groups, comprising healthy adults and those in receipt of healthcare, were conducted to explore the meaning, variation and perceptual experience of quality of life, and to test the face validity of the proposed domains and facets.
iii. Conceptual definitions, dimensional descriptions and illustrative examples were drafted for the agreed set of facets.
iv. Further focus groups, comprising members of the general population, people in contact with health services (with both acute and chronic conditions) and health professionals, were carried out to test the facet structure.
v. Aspects of the facet structure and some facets definitions were revised from the feedback received
vi. Focus group transcripts provided a source of suggestions for items, which were subsequently refined by question-writing panels, resulting in a global question pool of some 1,000 items (following deletion of duplicates, semantic equivalents and items failing to meet criteria).
vii. Conceptual clusters were formed within facets, which were rank ordered for importance and extent of information provided about quality of life within each culture.
viii. From the combined rankings, 231 items reflecting the facets and five items addressing overall quality of life and health formed the core *international* item set incorporated into the pilot WHOQOL instrument; in addition *national* items, specific to the language or culture of particular centres were appended where focus groups identified concepts not addressed fully by the core item set.
ix. Response scale anchors and intermediate point descriptors were generated and tested within each centre.
x. The format, instructions and mode of administration of the pilot measure were standardised, and it was field tested across the centres on groups of adults defined by sampling quotas linked to gender, age and health status.
xi. The pilot data were used to refine the facet structure and reduce the number of items, following initial frequency, reliability and correlation analyses.
xii. Finally, further field testing was carried out to establish the psychometric properties of the resultant 100 item instrument.

(For different aspects of instrument development methodology see WHOQOL Group 1993a, 1993b, 1994a, 1994b, 1995, 1998b; Szabo, 1996; Szabo et al, 1997; Skevington et al, 1997; Skevington, 1999; Skevington and Tucker, 1999; Skevington et al, 1999; Eser et al, 2000.)

Initial analysis suggested a six-domain structure for the pilot instrument (WHOQOL Group 1994a, 1994b, 1995). However, following full psychometric analysis on the large global dataset, including structural equation modelling, this was further reduced to a four-domain model, which comprised physical health (including independence), psychological (incorporating spirituality), social relationships and environment domains (WHOQOL Group 1998a, 1998b; Power et al, 1999).

The final version of the measure, the WHOQOL-100, added significantly to the resource bank of available instruments by providing a broad generic instrument that assessed both positive and negative facets of quality of life; was valid and reliable cross culturally; had a robust common item, facet and domain structure demonstrated across a wide range of countries with diverse economic, industrial, social and cultural profiles; and tapped what was characterised as the 'universal core concept of quality of life' (WHOQOL Group 1998b; Power et al, 1999).

In order for an internationally comparable instrument to be developed, the WHOQOL was designed essentially as a subjective measure of quality of life, intended to reflect an individual's own subjective perception of their position in life. As Orley et al (1998) pointed out, whereas it was possible to compare people's *satisfaction* with aspects of their lives across cultures, comparison of the actual living *conditions* of e.g. a psychiatrist in the USA and a pavement dweller in India was less tenable. The instrument has now been validated in number of different countries e.g. the Netherlands (De Vries and Van Heck, 1997) and the USA (Bonomi et al, 2000).

To promote breadth of potential use, the WHOQOL-100 was developed as a generic, rather than disease or disability specific instrument. Subsequently it has been used internationally in a number of research studies with different disease groups e.g. diabetes (Pibernik-Okanović et al, 1996); pain (Skevington, 1998); cancer (Tazaki et al, 1998); epilepsy (Amir et al, 1999); rheumatoid arthritis and sarcoidosis (Wirnsberger et al, 1999); and following liver transplantation (Kong and Molassiotis, 1999; O'Carroll et al, 2000a, 2000b). However, it was envisaged from the outset that supplementary modules might be added eventually, using the core WHOQOL methodology, for specific conditions e.g. epilepsy (Orley, 1994), cancer or AIDS (Saxena and Orley, 1997).

Finally, although the WHOQOL-100 was developed for an adult population, it was anticipated that supplementary modules or related instruments might be devised for other groups or populations, and examples of such developments which have been progressed include versions for both older adults (WHOQOL Group, in press) and children (Jirojanakul and Skevington, 2000). The WHO identified five priority areas for module development initially, which included 'persons with difficulty communicating e.g. persons with severe learning disabilities' (Szabo, 1996, p.361); however, this had not been taken forward at the time the current research commenced.

Quality of Life in Intellectual Disabilities

Schalock et al (1989) suggested that quality of life was such an important issue in human services that it might 'replace de-institutionalisation, normalisation and community adjustment as the issue of the 1990s' (p.25). The central position of quality of life in the evaluation of services for people with intellectual disabilities stems from the relative lack of capacity, and/or self-determination, of many individuals to control, or even influence, the course of their lives, such that support services may undertake a fundamental role in determining lifestyles and life experiences (Maes et al, 2000).

Renwick and Brown (1996) have suggested that the quality of life of adults with intellectual disabilities is related to the possibilities available to them in three fundamental areas of life: being; belonging; and becoming. Many authors (Janssen and Vreeke, 1995; Felce and Perry, 1996; Schalock, 1997; Cummins, 2001a) have stressed that the components of quality of life are the same for people with and without disabilities being 'those things that are common to all people and that constitute the human condition' (Brown et al, 1996, p.10); and that disability or handicapping conditions per se do not necessarily lead to differences in people's quality of life, although the specific meaning attached to quality of life components may vary from person to person as a result of the relative importance they attach to them, based on their previous experience, opportunities and constraints. However, as Schalock (2004) has pointed out:

> *...the concept of QOL is still emerging in the field of ID and ... currently there is still considerable debate about its application and impact (p. 214).*

Use of Generic Scales

From the literature, it appears that very few studies of the quality of life of people with intellectual disabilities have been carried out using generic scales developed in non-ID populations. Inter-alia, this may be accounted for by study rationales for instrument selection, the limitations of some measures to health related quality of life, and specific methodological problems associated with the validity and suitability of generic scales to the target population (see Fallowfield, 1990). However, one of the main problems in using generic measures of quality of life in the intellectual disabilities population may be related to the level of cognitive functioning, and associated high dependency, of many individuals. Intellectual disabilities may affect or limit capacity to communicate, to make self-determined choices, or to implement appropriate actions and decisions. Individuals may require extensive support to carry out everyday activities, and to interact with others and the environment; and if such support is required to engage in life experiences, similar support may be required to participate in assessment of life quality. One implication of this is that approaches to the systematic measurement of quality of life in this population may require options for supported or indirect responding, as well as direct response formats.

One of the most widely used generic assessments within the general population is the SF-36 (Ware and Sherbourne, 1992; Ware, 1996). This instrument was introduced in the 1990s, and contained 36 items measuring eight health-related quality of life dimensions: physical functioning; role limitations imposed by physical health; bodily pain; social functioning; general mental health (psychological distress and psychological well-being); role limitations due to emotional problems; vitality (energy and fatigue); and general health perceptions. Some subscales were dichotomous (requiring yes/no responses), while others had six-point response scales (with ratings from 'none' to 'very severe').

Jones et al (1997) reported the first study in which the measure was used with adults in the intellectual disabilities population. The purpose of the study was to examine the psychometric properties of the scale when adapted for use in a 'third party' format with direct care staff respondents. The adaptations were relatively minimal being confined to re-phrasing of the introductory words of items to reflect the response mode (i.e. from *'Do you...?* to *'Does the target person...?*). Acceptable internal reliability and a factor structure similar to that of the original scale used in direct format was reported. In addition, good-moderate inter-rater reliability was found for six out of eight subscales, however, two subscales (relating to role limitations due to physical health and emotional problems) were less reliable. Overall, the authors of the study concluded that staff were 'quite reliable in a series of judgements of general emotional states for the people they work with' (p. 33), but also recommended that the scale would require further adaptation prior to wider use with an intellectual disability population.

Population Specific Scales

A number of instruments have been developed specifically for the intellectual disabilities population for a wide range of purposes, including measures of normalisation, adequacy of services and support, life experiences and life satisfaction, as well as more global quality of life. However, in a review of 13 such scales developed since 1985, Cummins (1997a) suggested that only two of these scales meet the basic requirements for the measurement of quality of life according to a contemporary understanding construct, and noted that even the best of them required further development to incorporate themes emerging from theoretical work and research with this population.

Normalisation Indices

Several instruments have been devised to explore the extent to which services for people with intellectual disabilities provided life conditions that approached general population standards. The majority of such measures were founded on the principles of normalisation (Wolfensberger, 1972; O'Brien and Tyne, 1981) and attempted to assess the extent to which services provided a 'valued life'.

An example of a scale that is broadly representative of this approach is the *Questionnaire on Quality of Life*[3], developed by Cragg and Harrison (1984) and used subsequently in a number of UK studies (e.g. Donnegan and Potts, 1988; Fleming and Sternfert-Kroese, 1990; Dagnan et al, 1998). This measure comprises 70 items (53 directed at residents and staff, and 17 interviewer rated) divided between eight subscales: physical details of home; access to community; leisure opportunities; community integration; home routines; education and training; staff behaviour; and opportunities for choice and decision making. Although a full analysis of the psychometric properties of the scale has not been published, the scale has been reported to have good inter-rater reliability and internal consistency, and two broad factors reflecting 'service' and 'resident' centred quality of life (Dagnan et al, 1994).

It has been suggested that many instruments in this category were limited by the *service* (rather than individual) emphasis; by the lack of normative data; by the ideological focus based assumptions that achievement of externally adjudicated 'normalised' life circumstances would confer well-being (Cummins, 1997a); and by lengthy completion times.

Mainly Objective Measures

Some instruments have been developed to explore the life conditions of people with intellectual disabilities more directly, shifting the focus from particular service elements to individual service users life experiences. Many of these were based on normalisation principles also, and the extent to which people with intellectual disabilities enjoyed 'valued roles and opportunities'.

A widely used example of this scale type is the *Life Experiences Checklist* (LEC, Ager, 1990, 1998). This is an objective measure of quality of life, developed for use with adults with intellectual disabilities *and* with the general population, and has been used in several UK studies (e.g. Myers et al, 1997; Ager et al, 2001). This instrument has 50 items (which may be completed by ID clients or proxy staff) equally divided between five subscales: home, leisure, relationships, freedom, and opportunities. All items are scored positive (if true) or left blank. A full psychometric analysis has not been published; however good test-retest reliability (Ager, 1988; Look, 1987), inter-rater reliability (Ager et al, 1997) and validity (Murphy et al, 1996; Ager et al 1997) have been reported; and general population reference data based on a UK sample are provided.

A criticism sometimes levelled at such instruments relates to their primarily *objective* focus. However, as Ager and Hatton (1999) have noted, objective measures may reflect 'differential access to power and opportunity' (p.337); and in the context of vulnerable individuals, objective indices may have utility in challenging the influence of adaptation on purely subjective measures.

[3] Subsequently redeveloped as *COMPASS* (Cragg and Look, 1992), but including the same items.

Mixed Objective and Subjective Measures

Other instruments have been devised to explore the objective circumstances and subjective perceptions of people with intellectual disabilities, by seeking information about their situation and asking them how they feel about various aspects of their lives.

An example of this scale type is the American measure, the *Quality of Life Questionnaire* (Schalock and Keith, 1993). Although the authors have described the scale as a mixture of both subjective personal appraisal elements and objective functional assessment items (Schalock, 2004), a view endorsed by some commentators (e.g. Cummins, 1997a), others have described it as mainly subjective (e.g. Rapley and Lobley, 1995). This scale was developed specifically for people with intellectual disabilities. It was designed for administration within the context of a structured interview with ID clients, and there is scope to re-phrase items to assist comprehension. However, there is also the potential to derive a mean client score from completion of the scale by two proxy respondents. There are 40 items evenly distributed across four domains: satisfaction; competence/productivity; empowerment/independence; and social belonging/community integration. All items are associated with three point multiple-choice scales, scored from three (high) to one (low). The psychometric properties have been well defined, and the four-factor structure has been replicated with a British sample (Rapley and Lobley, 1995).

However, a number of criticisms may be made of this scale. Some items are strongly rooted in North American culture (e.g. *How successful do you think you are compared to others?*); other items are relatively abstract and complex (e.g. *Do you feel your job or other daily activity is worthwhile and relevant to yourself or others?*); the facility to re-phase items introduces the potential for loss of standardisation; and the responses options (which differ for each item) are complex and lengthy also (e.g. Item: *What about your opportunities for dating or marriage?* Response options: *I am married, or have the opportunity to date anyone I choose; I have limited opportunities to date or marry; I have no opportunity to date or marry*). Finally, it has been suggested that the utility of the measure is limited by the associated narrow conceptualisation of quality of life, and its focus on work (25% of items) basic needs, and fulfilling responsibilities (Cummins, 1997a).

Combined Subjective and Objective Measures

Finally, some instruments have been developed to include a combination of distinct objective and subjective quality of life components, in an attempt to represent the construct comprehensively within a single measure.

Arguably, the best example of such a scale is the Australian measure, the *Comprehensive Quality of Life Scale* (ComQol, Cummins, 1993). It has three parallel forms, of which one is for adults in the general population (ComQol-A) and one is for adults with intellectual disabilities (ComQol-ID) allowing for

direct comparisons between groups. Three modifications were made to the standard adult version to customise it for intellectual disabilities: pre-testing of the ID adult's capacity to use Likert scales, a 'faces' version of the response scales; and a parallel scale for third-party responses to enable the scale to be used with individuals unable to meet the requirements of subjective responding (Cummins, 1991). There are 35 items, 21 objective and 14 subjective divided into seven domains (which were generated from a review of the literature): material things; physical well-being; productivity; intimacy; safety; place in society; and emotional well-being. Objective domains are measured by summing the scores of three items linked to five-point Likert scales; and subjective domains are measured by the product of perceived importance (rated on a five-point scale) and satisfaction (rated on a seven-point *delighted-terrible* scale). The psychometric properties of all three versions of the scale (general adult, ID adult and adolescent) have been reported (Cummins, 1994; 1997b; Gullone and Cummins 1999).

Perhaps the most interesting features of this particular instrument are the modifications made for use with an intellectual disability population. However, Cummins (1997b) makes two criticisms of his scale: that much of its reported use has been confined mainly to one research group, although the instrument has been used in the UK (Hensel et al, 2002); and that the availability of psychometric data remains limited. However, more recently, it has been suggested that unless evidence to support the notion of the product of importance and satisfaction is reported, the seven importance items could be dropped, and that some reduction could be made to the 21 objective items (Hagerty et al, 2001). Finally, others have noted that some of the so-called objective scale items require subjective judgements that may be difficult for ID clients with limited experience to make, and may lack external verification e.g. *How many things do you own compared to other people?* (Hensel et al, 2002).

Measurement Issues and Problems

As this brief review of typical examples of quality of life instruments shows, there are a number of issues and problems in relation to the measurement of quality of life in intellectual disabilities.

Relevance of Facets

The domains and facets of many quality of life scales have not been empirically determined, but have resulted from distillations of taxonomies already in the literature, from various researchers' individual (and sometimes highly personal) conceptualisations of quality of life, or from the translation of the dimensional structure of a generic scale to the ID population. Day and Jankey (1996) suggested that the starting point for measuring the quality of life of individuals should be the involvement of the *target respondents* in identifying the factors that are most important in defining the circumstances of their lives.

There may be particular aspects of quality of life that are more important in the assessment of quality of life of people with intellectual disabilities, which may be construed as supplementary to 'core' facets, but which are required to achieve a comprehensive and more valid general assessment. For example, Goode and Hogg (1994) have argued for the importance of high quality medical and educational services for people with profound and multiple developmental disabilities. However, as Schalock (1994) has noted, the basis for the facet content needs to be evaluated.

Requirement for Objective and Subjective Dimensions

Although some notable attempts have been made to combine objective and subjective dimensions within a single instrument, the majority of quality of life scales are either primarily objective or predominantly subjective.

Many people with intellectual disabilities may have experienced the restricted life conditions of institutional care, or may reside within the relatively limited horizons of some community-based services. Therefore, it has been suggested that complementary objective and subjective measures are required to safeguard the vulnerability of the client group and avoid the masking of poor life conditions by high life satisfaction scores in the context of adaptation (Felce, 1997; Ager and Hatton, 1999; Felce and Emerson, 2000). The importance of both dimensions has been observed from the reverse perspective also, in that favourable life conditions do not necessarily guarantee a 'good life' (Vreeke et al, 1997) and may not result in high levels of subjective well-being.

Cummins (1998, 2000) has argued for the prominence of subjective measures, supporting his position by conceptualising a homeostatic mechanism, which controls subjective well-being within a narrowly defined range under diverse personal circumstances, but which is defeated when objective life conditions become aversive thereby providing a signal of problems. However the level of adversity that might defeat subjective homeostasis has not been explored systematically (Cummins, 2001a), and the threshold of homeostatic failure may be subject to individual differences. As Felce and Perry (1996) have pointed out, satisfaction may prove to be 'an unresponsive life quality indicator, sensitive only to gross and immediate changes in life conditions' (p.55). Similarly, the effectiveness of a combined dimensional measure in highlighting problems in life conditions, and life experiences, compared to the efficiency of separate single measures has not been evaluated.

In similar vein, Haas (1999) has argued that although quality of life is primarily about individuals' subjective sense of well-being, in some circumstances, objective measures may have additional value in serving as a proxy assessment for those unable to communicate subjective perceptions.

Challenges of Scale Administration

Finally, there are a variety of reliability and validity problems surrounding the administration of quality of life measures in the intellectual disability population, depending on the available response mode.

Direct interviews are possible only with clients who have the cognitive capacity and communication skills to self-report, and the behavioural skills and controls to participate directly in scale item completion (Raphael, 1996). However, even when self-report is feasible, there may be issues of socially desirable responding; and also problems related to response bias e.g. acquiescence (Sigelman et al, 1981); the tendency to select the last option presented (Sigelman and Budd, 1986); and 'candidate answers' (Antaki and Rapley, 1996). However, in relation to acquiescence, researchers have suggested that the phenomenon may be re-conceptualised as pseudo-acquiescence motivated by interviewers' reformulation of questions in the quest for acceptable answers (Rapley and Antaki, 1996).

In the context of individuals with severe receptive or expressive communication problems or cognitive limitations, which make direct interviews impossible, an indirect proxy approach may be required, and may be the only method available to approximate to self-report (Goode and Hogg, 1994). In such cases, there may be concerns about reliability in terms of potential divergence of view between the ID client and the proxy, or bias linked to socially desirable responding, or related to proxies' own interests. Research findings on the degree of agreement between clients with mild to moderate intellectual disabilities and proxies are inconsistent and controversial. Some studies have found acceptable levels of agreement on some measures and/or dimensions (Stancliffe, 1999; McVilly et al, 2000); but others have found lower rates of concordance (Rapley et al[4], 1997). Although proxy information cannot be regarded as a substitute for self-report, some authors have pointed out that for individuals with more severe intellectual disabilities, the alternative to proxy report may be effective disenfranchisement from the quality of life assessment process (Hatton, 1998), at least in relation to quantitative measures of subjective quality of life (Hatton and Ager, 2002). Furthermore, it has been suggested that differences between the views of ID clients and proxies may not necessarily indicate that the proxies are wrong, but may reflect merely differences in opinion (Stancliffe, 1999).

Summary

Quality of life is an ancient construct that has been used to support a range of perspectives and policies over the years. It has been variously defined, but has come to be regarded as a multi-dimensional concept, having both objective and subjective indicators (Felce, 1997; Schalock, 2004).

[4] This study employed a very small sample of 13 ID clients.

The inclusion of quality of life assessment as a variable in the evaluation of health and social care introduced a more holistic orientation, and widened the focus of treatment/care outcomes. Approaches to the measurement of quality of life have included both generic and disease or population specific instruments, many of which were developed in the industrialised first world countries, and some of which have identified limitations (Cummins, 1997a). In addition, quality of life assessment in intellectual disabilities presents a number of unresolved challenges (Schalock, 1994).

The World Health Organisation adopted a new approach to the development of a cross-cultural measure of quality of life, and the resulting instrument, the WHOQOL, has provided a psychometrically robust measure, with a facet and domain structure considered to reflect a universal, or core, concept of quality of life (Power et al, 1999). The potential for future development of a version of the measure for people with intellectual disabilities was recognised at an early stage, but has not yet been progressed by the WHOQOL group.

Implications for Current Study

The closure of all Scottish hospitals for people with intellectual disabilities, and their replacement by a range of social care alternatives, is scheduled for 2005. Over the years, de-institutionalisation research has demonstrated fairly modest (although mainly positive) outcomes on traditional indicators; but more recently, the potential for quality of life studies to re-focus on the evaluation of personal satisfaction from the perspective of the ID clients has been noted. In this context, there is considerable interest in information about the quality of life of adults with intellectual disabilities in the first wave of the Scottish resettlement process, to evaluate the impact of the major service change, and to inform future policy direction.

Although there were a variety of generic and population specific quality of life instruments available for use in such a study, many had shortcomings. The development of the WHOQOL, its breadth, universality, and related iterative methodology, provided an attractive starting point for considering a new measure of quality of life for adults with intellectual disabilities. Cummins (2001b) has noted the danger of creating scales solely for disadvantaged groups, and asserted that 'any instrument held to measure the quality of life of the general population must comprise items which most people consider relevant to the construct' (p.7). Felce and Perry (1996) have stressed the importance of developing a common approach to quality of life, which is applicable to all groups within society, so that data from specific groups may be compared to the population as a whole, and interpreted with confidence, such that social policy may respond where 'conspicuous inequality' (p.62) is revealed. The aim to devise a WHOQOL-ID was consistent with these perspectives.

Therefore, the current study set out to explore whether the generic form of the WHOQOL could be customised for adults with intellectual disabilities; to determine if supplementary facets were required in order to assess quality of life adequately in this population; to investigate the suitability of the format for the target population, and any adaptations required to meet the criteria for simplicity and intelligibility of items and response scales; to determine if an appropriate balance of comprehensiveness and brevity could be achieved (e.g. by focussing on the abbreviated version of the WHOQOL); and to evaluate the adequacy of the psychometric properties of the new measure.

As the WHOQOL is primarily a subjective measure, in view of the vulnerability of adults with intellectual disabilities to adaptation, and hence the potential for poor life conditions or impoverished experiences to fail to moderate life satisfaction, a second objective quality of life measure (the LEC) was included in the study also.

An introduction to the overall research aims, design and methodology of the study is presented in Chapter 4; and the detailed methodology of the component pilot, subsidiary, and main studies is presented in subsequent chapters.

Chapter 4

Overview of Research Design and Methodology

The initial impetus for the current study was the closure of a large learning disability hospital and the resettlement of the former residents, all of whom were adults with intellectual disabilities, to alternative community care. Two fundamental questions arose from the successful implementation of this strategic change programme:

1 Did the programme bring about *positive change* for the individuals involved: were there differences in the quality of life of these ID clients now that they had relocated from the institution and were in receipt of social care in a range of alternative settings?

2 Did the programme bring about *enough change*: were there differences (still remaining) in the quality of life of these ID clients in the community compared to their non-disabled counterparts (the general public) living in similar neighbourhoods?

The design and methodology of this study were geared to addressing these basic questions, but with a wider focus informed by the research literature on both resettlement and quality of life. An introduction to the study and an overview of the basic methodology is presented in this chapter; and more detailed descriptions of the component parts of the study are provided in subsequent individual chapters.

4.1 Background[1]

In 1924, the first hospital in Scotland to be purpose built for the care of people with intellectual disabilities (then called 'mental deficiency') was established as part of the implementation of the Mental Deficiency and Lunacy (Scotland) Act 1913, which required the provision of special institutions for this client group, quite separate from the 'asylums' for those with mental illness. As well as being an NHS treatment facility, the hospital was a home, a work place, an activities centre and a social world for hundreds of adults with intellectual disabilities for seventy-five years. It was designed as a 'village colony' and many residents spent their whole lives within the limited horizons of the institution. At its peak, the hospital had one thousand beds; however the bed complement reduced over the years, particularly through the 1970s and 1980s, as a result of developments in social policy, changes in admission practice and successive small-scale resettlement initiatives.

[1] From NHS archives and hospital's patient information booklets (undated) c.1975-1990

In May 1999, this first learning disabilities hospital to open in Scotland became the first to close also, following a five-year strategy to relocate all the remaining residents, and reprovide all the care and support services, in a range of community locations. When the major change programme began in 1994, there were 336 people in the hospital.

Gender

Almost two thirds of the resident group were male (62.5%) and only one third was female (37.5%). This ratio of approximately 2 males: 1 female was higher than the average prevalence reported by gender[2] (McLaren and Bryson, 1987), but may have reflected the combined impact of former admission and discharge policies, and the higher rates of challenging behaviours (e.g. aggression) in males with intellectual disabilities generally (Emerson, 2001), and in this sample (see dependency below).

Age

As shown in Table 4.1, on average, the male residents were almost a decade younger than the female residents, with a mean age of male residents of 46.1 years (*SD* 16.35) and a mean age of female residents of 54.1 years (*SD* 19.95). However, a large and almost identical age range (from around twenty to just over ninety) was reflected within both gender groups.

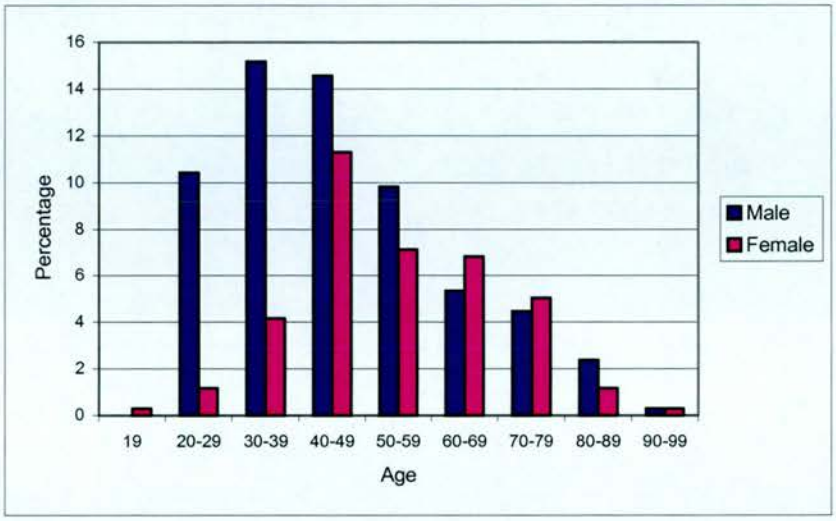
Table 4.1: Hospital Residents by Age (at 1994)

Gender	*N*	Age Range	Mean Age	*SD*
Male	210	20-91	46.1	16.35
Female	126	19-93	54.1	14.95
Total	336	19-93	49.1	16.28

The full age distribution of residents is presented in Figure 4.1. Overall, the residents were becoming an ageing population with approximately 26% aged 60 or over; 43% aged between 40 and 59; and 31% aged below 39 years. In the older age group, 12% were aged 60-69; 10% were aged 70-79; 4% were aged 80-89; and 1% were aged ninety or over, reflecting the increased longevity of people with intellectual disabilities (Hogg et al, 2000) with the associated potential for a range of increased health care needs linked to ageing (e.g. physical health problems such as cancer and heart disease; and mental health problems such as dementia).

[2] Average ratio 1.2 males: 1 female for severe intellectual disabilities; and 1.6 males: 1 female for mild intellectual disabilities

Figure 4.1: Distribution of Hospital Residents by Age (at 1994)



Dependency

Overall, the resident group demonstrated relatively high support needs. Detailed staff ratings of the dependency of residents are presented in Table 4.2. On the basis of this information, approximately 41% of residents could be categorised as high dependency; 34% could be categorised as medium dependency; and only 25% as low dependency.

Table 4.2: Dependency of Hospital Residents

Dependency Category [3]		Male (*N* = 197)		Female (*N* = 118)		Total (*N* = 315)	
		N	%	*N*	%	*N*	%
1	CAN and Able[4]	33	16.8	16	13.6	49	15.6
2	Non Ambulant Only	0	0	0	0	0	0
3	Severe Behaviour Problems Only	11	5.6	2	1.7	13	4.1
4	Elderly Low Dependency	9	4.6	8	6.8	17	5.4
5	Elderly Dependency	26	13.2	22	18.6	48	15.2
6	Medium Dependency	35	17.8	24	20.3	59	18.7
7	High Dependency	42	21.3	30	25.4	72	22.9
8	SBP[5] and Medium Dependency	17	8.6	7	5.9	24	7.6
9	SBP and High Dependency	24	12.2	9	7.6	33	10.5

Missing cases: 21 (male = 13; female = 8)

[3] Bryn-y-Neuadd Degree of Dependency Rating Scale (Cadell and Woods, 1984) an extension to the Wessex Schedule (Kushlick et al, 1973)
[4] Continent, Ambulant, No behaviour disorder; and with basic self help skills
[5] Severe Behaviour Problems

Resettlement Outcomes

The range of outcomes for the former hospital residents in 1999, at the time of hospital closure and the end of the strategic change programme, is presented in Table 4.3.

Sadly, 34 residents (10%) died prior to transfer to community care; and by 1999, a further 18 (5%) had died following resettlement. Of the remaining 284 clients, 45 (16%) transferred from the hospital to various forms of NHS continuing care, including medium stay treatment facilities and longer stay 'healthcare' houses; 13 (5%) moved into local authority residential care; 18 (6%) moved into nursing homes; and 28 (10%) moved to vacancies in existing projects, single tenancies, informal care arrangements with their families, or placements out of the region (closer to family or other original domicile links). However, 180 clients (63%) relocated to new social care homes designed specifically to meet their care and support needs in local communities.

Table 4.3: Relocation of Hospital Residents (at 1999)

Outcome / Resettlement Placement	*N*	%	Valid %
Deaths (pre-community transfer)	34	10.1	-
Deaths (post-community transfer)	18	5.4	-
NHS houses/medium stay treatment units	45	13.4	15.8
Local Authority hostels/residential homes	13	3.9	4.6
Nursing Homes	18	5.4	6.3
Individual places (existing projects)	19	5.7	6.7
Single tenancies	3	0.9	1.1
Informal carers (family)	4	1.2	1.4
'Out of Region' projects	2	0.6	0.7
Social care homes	180	53.6	63.4
		(*N* = 336)	(*N* = 284)

The assessments that underpinned the discharge and resettlement plans for many of this latter group of clients had indicated the need for sophisticated and individually tailored care packages to support ordinary community lifestyles and promote high quality outcomes. The model of social care provided was delivered in a range of staffed (in some cases intensively staffed) homes, typically domestic in size and scale, in a range of localities (both urban and rural) across a geographical area with a population base of around 700,000. (See Chapter 7 for detailed information on social care accommodation.) The focus of interest of the current research programme was the quality of life of these clients who transferred to the new social care homes in local communities.

4.2 Research Aims

The principal aims of the current research were to:

1 Assess the quality of life of an index cohort of adults with intellectual disabilities currently in community care settings (but formerly hospital residents) and explore their degree of satisfaction with the lifestyle and life experiences associated with local community based supported living

2 Compare assessment data from the group of community clients with assessments of the quality of life of a similar group of current hospital in-patients (matched with the index cohort for age, gender and dependency) in relation to a learning disability hospital which had not yet implemented a full resettlement programme

3 Compare both datasets with assessments of the quality of life of a group of the general population (matched with the index cohort for age, gender and locality).

In order to achieve these aims, subsidiary objectives were to:

4 Adapt the World Health Organisation quality of life measure, the WHOQOL, for adults with intellectual disabilities and establish the set of quality of life facets required to provide a comprehensive assessment of the quality of life of this population

5 Develop and pilot the adapted instrument for subsequent use as one of the measures of quality of life in relation to the main study groups of community clients, hospital residents and general public

6 Evaluate the psychometric properties of the new scale, the WHOQOL-ID, in relation to the main study dataset

7 Carry out a brief survey of the community accommodation in which the community cohort of adults with intellectual disabilities resided; collect staff views on the suitability and effectiveness of the accommodation and identify those aspects associated with positive or negative outcomes for clients (if any).

4.3 Design and Methodology

The research was formulated as two linked pilot studies, a subsidiary study and a larger main study. A combination of qualitative and quantitative methods was used to address the principal research aims and achieve the subsidiary objectives, guided by a range of underlying assumptions and informal hypotheses. An outline of the overall study is presented (in procedural order) in Table 4.4.

Table 4.4: Research Outline

Study Element	Purpose	Aim	Assumptions
Pilot study 1	Identify quality of life facets for ID group and develop WHOQOL-ID	4	Additional items (representing themes over and above the WHOQOL facets) might be required for a comprehensive assessment of the quality of life of adults with intellectual disabilities Item and response scale revisions might be required also, to adapt the instrument fully for the client group
Pilot study 2	Pilot WHOQOL-ID in small field trial	5	Further revision or refinement might be required to improve suitability, intelligibility or scale reliability
Subsidiary study	Identify characteristics of the community accommodation	7	None - basic survey of accommodation to collect information from staff
Main study	Measure quality of life of three groups: ID clients in hospital and the community, and general public (using WHOQOL-ID and other measures)	1 - 3	The quality of life of community clients might be superior to that of their hospital counterparts; but the quality of life of the general public might be superior to that of both hospital residents and community clients
	Evaluate psychometric properties of new WHOQOL-ID	6	Additional quality of life facets (if required) might be linked to existing WHOQOL domains, or might represent one or more additional domains or add-on 'modules'

Pilot Studies

The methodology employed for pilot studies one and two followed closely that established by the WHOQOL Group during the development of the original WHOQOL-100 (WHOQOL Group 1994, 1995, 1998b) and WHOQOL-BREF (WHOQOL Group 1998a) scales and recommended in the Draft WHOQOL User Manual (WHO 1998).

Focus Groups (comprising adults with intellectual disabilities, professionals working with the client group, and persons having a relative with intellectual disabilities) were convened to identify the aspects of life, or quality themes, that contributed most to the quality of life of adults with intellectual disabilities; and to check the relevance of the WHOQOL facets for the client group. Subsequently, an iterative approach (involving research expertise, the views of health and social care professionals and feedback from adults with intellectual disabilities) was adopted to adapt, revise, and consolidate the intellectual disabilities version of the WHOQOL at all stages of development.

Subsidiary Study

The methodology used for the subsidiary survey of community accommodation was a descriptive design using a structured questionnaire format completed by face-to-face interview. The content of the questionnaire was driven by a set of fixed interests (from a sponsoring body) and the item format was a mixture of structured, semi-structured and open-ended questions (used as a follow-up, or to capture additional detail).

Main Study

The methodology used for the main study was a quasi-experimental three level between-subjects design with group matching on the key variables of age, gender and dependency (hospital residents and community clients) and age, gender and residential locality (community clients and general public). Although the main focus of interest was potential differences in the dependent variable (quality of life) in levels one and two of the independent variable (clients with intellectual disabilities in hospital and in the community), a third level (general public) was included to provide a normative comparison group. Efforts were made to achieve a balanced design, with approximately equal numbers (c. 200) for each of the three levels of the independent variable.

As the study was planned in relation to interest in a specific cohort of adults with intellectual disabilities (former hospital residents already transferred to the community), the relatively stronger within-subjects repeated measures design was not feasible. However, this may have presented problems of possible order or carry-over effects; and group matching would have remained an issue in relation to the comparator public group.

The quality of life measures were completed by face-to-face interview (hospital residents and community clients) and as a self-completed postal survey (general public). The face-to-face interviews were carried out directly with those ID clients with the capacity to participate and respond, and indirectly with proxy staff on behalf of those ID clients without such capacity.

4.4 Participants

There were 46 focus group participants in pilot study one; 34 adults with intellectual disabilities took part in the field trial of the WHOQOL-ID in pilot study two; 51 projects were involved in the subsidiary study of community accommodation; and there were 625 participants in the main study including 471 adults with intellectual disabilities (213 hospital residents and 204 community clients) and 208 members of the general public. All the individuals with intellectual disabilities that participated in the research were adults (over eighteen years of age) and all were in receipt of health or social care.

Pilot Study One

Purposive sampling was used to establish suitably sized focus groups with an appropriate homogeneous mix of the three main participant types: ID clients; professionals with experience of working with intellectually disabled adults; and relatives of adults with intellectual disabilities. In addition, an opportunistic sample of professionals in training (trainee clinical psychologists) became available and was added as a fourth participant type.

Two client focus groups, separately comprising individuals with backgrounds of health and social care were consulted to capture a broad and appropriate range of ideas and experiences about quality of life themes. Similarly, two staff focus groups were held involving qualified staff with experience of a wide range of intellectual disabilities services including both challenging behaviour (e.g. behaviour problems, offenders) and 'special needs' (e.g. severe and profound intellectual disabilities, complex physical disabilities).

Pilot Study Two

The participants of the field trial of the WHOQOL-ID were recruited by a mixture of purposive and convenience sampling. The rationale of the purposive element was twofold: firstly, to avoid any overlap between the pilot and subsequent main study participants; and secondly, to ensure an adequate mix of participants from the target population in both hospital and community settings. The convenience element of the sampling was based on the availability of, and ease of access to, local health and social care projects.

Subsidiary Study

The 'participants' of the subsidiary study were the social care homes (projects) in which the community group resided. As the community group was a fixed cohort there were fifty-one such projects only, therefore no sampling was involved and all fifty-one projects were included in the study.

Main Study

The plan for the main study involved the recruitment of participants on the basis of a mixture of criterion referenced inclusion (index community clients) purposive sampling (for group matched hospital residents) and stratified quota sampling (for group matched members of the general public). However, as the available sample of hospital residents was limited, it was not clear if this could be achieved fully.

Community Clients

No sampling was undertaken in relation to the index community group. This was a fixed and finite cohort of adults with intellectual disabilities, all of whom had transferred from hospital to community care between 1994 and 1999, and now lived in social care homes within the study region.

In the initial stages of project planning it was anticipated that the group of 180 clients who transferred to social care homes from the large hospital (as described above) would be the potential participants for the main study community group. Two local authorities, both of which had indicated support for the research, were responsible for the purchase of care for these clients. However, a third local authority with responsibility for an additional group of 39 clients, all residing in similar community settings in the region, and all discharged from a smaller neighbouring learning disabilities hospital during the same timeframe, requested that these clients were included as potential participants for the community group. Ultimately, a total of 204 community clients from this potential pool of 219 participated in the study. (The remaining 15 clients were followed up, but three had died, ten had moved to alternative forms of care, and two were approached but declined to participate.)

Hospital Residents

The hospital selected as the site for recruitment of the comparator hospital group of participants was very similar to the hospital in which the community group had formerly resided. This second hospital was about to undergo a large-scale resettlement initiative and thus the timing of the research approximated to the time at which pre-discharge assessments would have been carried out if a within subjects design had been possible in relation to the index community group.

When the hospital was first approached in principle, as a possible research site, there were 299 residents as potential group matches for the index community clients on the basis of age, gender and dependency. It was envisaged that around 150-160 community clients would be community group participants (initially estimated on the basis that some of the originally targeted 180 clients could have died or moved on, or might refuse participation). Therefore it was anticipated that the pool of 299 hospital residents would provide sufficient numbers for group matching. However, by the time the process of participant recruitment began, the potential pool of hospital residents had reduced to 280; and contemporaneously, the size of the potential community group had increased due to the additional group of 39 clients. As work progressed, the number of hospital residents decreased further as six individuals died and 58 people were discharged during the initial waves of resettlement. This reduced the potential hospital participants to 216. Ultimately, a total of 213 hospital residents participated in the study and three declined to participate in the research.

As the available numbers of potential participants in both the hospital and community groups converged, group matching on the three key variables (age, gender and dependency) was no longer feasible. Therefore, the planned design was amended to include appropriate testing of the similarity of the two groups, and to incorporate statistical control of these variables if required.

General Public

The general public participants were recruited on the basis of stratified quota sampling. Sampling parameters were drawn up to provide a match between the general public group and the index community group on the variables of age (in ten year bandings), gender and locality (defined by residential postcodes). The sampling frame was the relevant health authority Community Health Index (CHI), from which quotas of potential general public participants were identified through blind access. As the general public were to receive postal questionnaires, and as the measures were estimated to take approximately fifteen to twenty minutes to complete, it was anticipated that the response rate might be low. Therefore approximately 1,000 members of the public were approached with the aim of achieving sufficient responses to match the size of the community and hospital groups. Although the response rate differed slightly across each cell of the sampling frame, ultimately there were 208 members of the general public who participated in the study.

4.5 Measures

Three types of measures were used within the overall study: quality of life assessments; dependency measures (adults with intellectual disabilities); and a housing questionnaire (community accommodation).

Quality of Life

There were two quality of life measures used in the main study: the pilot WHOQOL-ID (developed within the framework of the study and the subject of the field trial in pilot study one) and the Life Experiences Checklist.

WHOQOL-ID

The primary quality of life measure was the WHOQOL-ID. This was an adaptation for an intellectual disabilities population of the WHOQOL-BREF (WHOQOL Group 1998a), which was developed as an abbreviated version of the original WHOQOL-100 (WHOQOL Group, 1994b, 1995, 1998b).

The WHOQOL-100 is an international quality of life measure based on a multi-dimensional model of quality of life and a multi-cultural approach to the identification and development of facets and items within four core domains (physical, psychological, social relationships and environment). The WHOQOL-

100 comprises twenty-four facets (ninety-six items, four per facet) and four general questions on overall quality of life and health. Detailed analysis of the psychometric properties of the instrument (WHOQOL Group, 1998b) indicated that it provides a valid and reliable measure of quality of life in a range of diverse cultures.

The WHOQOL-100 provides a detailed assessment of quality of life, but it was thought to be too lengthy an instrument for some purposes. Therefore, an abbreviated version of the instrument, the WHOQOL-BREF (Field Trial Version, 1996) was developed to provide a shorter assessment of quality of life allowing for reduced completion time where this may provide a better fit with clinical or research purposes. The shorter version of the instrument also produces scores for four quality of life domains (physical, psychological, social relationships and environment) as well as having one facet on each of overall quality of life and general health. Although only one-quarter of the length of the original WHOQOL-100 (incorporating one item from each facet), trials in twenty field centres across eighteen countries have shown it to be a valid and reliable alternative to the original instrument at domain profile level (WHOQOL Group, 1998a).

The WHOQOL-BREF version of the instrument was selected for adaptation for an intellectual disabilities population because its significantly reduced length made it more suitable for direct use with individuals with limited cognitive abilities, attention deficits or communication difficulties. In addition, the international perspective and collaboration that provided the context for the development of the WHOQOL project produced the suggestion that a universal core concept of quality of life was being tapped by the instrument.

A copy of the WHOQOL-BREF is presented at A4.1 in Appendix 4.

Life Experiences Checklist (LEC)

The Life Experiences Checklist (Ager, 1990, 1998) provides an objective measure of how much people with intellectual disabilities participate in the events and experiences common to other members of the general population. It is based on the principles of normalisation and the extent to which people with intellectual disabilities enjoy 'valued' roles and have the opportunities for a variety of experiences which are routinely valued by others. The instrument is structured around five themes: home, leisure, relationships, freedom and opportunities; has fifty items, ten within each of the five domains; and is designed for either self or proxy completion. Detailed analyses of the scale and subscale structures have not been reported; however the manual provides data on test-retest reliability (Ager, 1988; Look, 1987), inter-rater reliability (Ager et al, 1997) and validity (Murphy et al, 1996; Ager et al 1997) that indicate adequate performance on these indices within UK settings and culture.

A copy of the LEC (2nd edition) is presented at A4.2 in Appendix 4.

Dependency

Three dependency measures were either carried out as part of the study, or were made available in the form of raw data, having been used within the settings for other related purposes within the study timeframe.

Wessex Schedule

The Wessex Schedule (Kushlick et al, 1973) is a method of rating the dependency and behaviour characteristics of people with intellectual disabilities for use in large-scale surveys. The measure has two core subscales: social and physical incapacity (SPI) comprising ratings within domains of incontinence, mobility and behaviour disorder; and speech, self-help and literacy (SSL). These subscales are derived from scores on a fixed set of items, but the instrument may be used flexibly, with other items added for specific purposes or research interests. Together the core subscales reflect an individual's requirement for support from others, and the extent of certain maladaptive or disruptive behaviours that may impact on those with whom they live, or from whom they receive care and support. The authors of the schedule reported a high degree of inter-rater reliability and some evidence of face validity based on data drawn from a census carried within in the Wessex (Health) Region where the instrument was developed. The Wessex subscales have been used in large surveys of hospital residents during the initial phases of many hospital resettlement strategies in the UK (Blunden, 1975; Martindale, 1976; National Development Group, 1978).

A copy of the version of the Wessex (including the core items and subscales) used in the current study is presented at A4.3; the Wessex domains and ratings are shown in Table A4.4; and the core Wessex outcome categories are shown in Table A4.5, all of which appear in Appendix 4.

Bryn-y-Neuadd Degree of Dependency Rating Scale (DDRS)

The Bryn-y-Neuadd Degree of Dependency Rating Scale (Cadell and Woods, 1984) is an extension of the Wessex Schedule and provides a method of deriving nine categories of dependency from the Wessex core scores. Although psychometric data have not been reported, the DDRS was found to be useful in planning service needs and related costs within the 'All Wales Strategy' a major development programme to resettle people with intellectual disabilities from hospitals throughout Wales (Welsh Office, 1982, 1983).

A copy of the Bryn-y-Neuadd Degree of Dependency Rating Scale categories, and the relationships between these and the Wessex Schedule ratings, is presented at A4.6 in Appendix 4.

Dependency and Needs Information System (DANIS)

The Dependency and Needs Information System is a method of describing the characteristics of people with intellectual disabilities in continuing care, developed by the Information and Statistics Division (ISD) of the National Health Service in Scotland. The measure comprises three categories of care need (major training need, complex care need and behavioural difficulties) and three categories of dependency (feeding, toileting and transferring position). In addition, a variety of supplementary information is collected on physical disability, incontinence, visual and hearing impairment, communication problems and mobility. The instrument was devised by ISD to provide a measure of dependency for use in relation to hospital resettlement and the related contracting of services for people with intellectual disabilities, as well as for monitoring the balance of care between hospital, nursing home and community settings. The measure is similar to the Wessex and the derivative DDRS (perhaps its natural forerunners), but is more specifically targeted at collecting the information required to assist and support hospital resettlement.

The DANIS ratings were available for 98% of the participants in the hospital group, as the measure had been integral to the contemporaneous resettlement planning for these individuals. However, DANIS ratings were available for only 49% of the community group: although the instrument had been piloted in one of the two former hospital settings (the larger), many people had relocated to the community prior to this. As there were so many missing cases in the community cohort, the measure could not be used in the context of the between groups design. Nevertheless, the available data were used to carry out a smaller within-subjects comparison of the DANIS and the Wessex/DDRS using a cross sectional correlational design.

The copy of the definitions of the DANIS special needs and dependency items is presented at A4.7; the original fourteen DANIS groups and categories are presented in A4.8; and the five main aggregated outcome groups (suggested by ISD as the most useful outcome format) is shown at A4.9, all in Appendix 4.

Community Accommodation

A basic Project Description Form and a custom designed Housing Questionnaire were used to collect information as part of the survey of the accommodation in which the community group resided. The structure and content of these are described in detail in Chapter 7 (within the context of the subsidiary study) and both instruments are presented in full in Appendix 7.

Additional information on various aspects of the methodology, participants and measures is included in chapters 5, 6, 7 and 8, in which the pilot, subsidiary and main studies are described in detail.

Chapter 5

Pilot Study 1: Establishment of Quality of Life Themes

The WHOQOL-100 was developed within the inclusive framework of an international collaboration of countries with diverse economic, industrial, social and cultural profiles; and tapped what was characterised as the 'universal core concept of quality of life' (see Chapter 3). Nonetheless, the potential for customising the instrument for use with specific populations, by supplementing the core scale with additional facets or modules, was acknowledged from the outset (WHOQOL Group, 1994b; Szabo, 1996; WHOQOL Group 1998b).

Therefore, the aims of the first qualitative pilot study were to:

1 Test the relevance of the WHOQOL quality of life facets for adults with intellectual disabilities

2 Identify the requirement for any such additional facets for this population

3 Establish the set of quality of life themes necessary to provide the basis for development and adaptation of the instrument for this client group.

5.1 Conceptual Framework

The present study drew on the conceptual framework used by the WHOQOL Group, which emphasised the multi-dimensional nature of quality of life (including physical, psychological, social and environmental domains) with particular reference to the individual's subjective view of the impact of these dimensions in relation to personal values and cultural norms. Given the internationally established applicability of the 24 quality of life facets contained within both the WHOQOL-100 and WHOQOL-BREF, it was anticipated that the majority of these facets (if not all) would play a valid part in assessment of the quality of life of adults with intellectual disabilities. Therefore, the conceptual definitions of the quality of life facets described in the Draft WHOQOL User Manual (WHO, 1998) provided the starting point for the pilot study.

However, it was envisaged that some dimensions of the life experience of adults with intellectual disabilities might differ as a result of handicapping conditions imposed by cognitive deficits and/or associated physical disabilities, possible variation in societal response, or differential personal capacity (or need for support) to realise certain norms or values, or achieve certain goals or standards. Therefore, the appropriateness and adequacy of the WHOQOL facets for the intellectual disability population was explored using an iterative process in the context of focus groups.

5.2 Focus Group Design and Methodology

Focus group interviews have been described as the involvement of a limited number of people, selected because they possess certain characteristics, to provide data of a qualitative nature, in a focussed discussion (Krueger, 1996).

The general methodology of focus groups may be distinguished from that of other group discussions by the application of a structured and sequenced process, which is moderated to maximise opportunities for all participants to interact in a supportive and non-judgemental environment.

As Krueger (1996) noted, focus groups may be used for a variety of purposes within the framework of quality of life assessments e.g. to develop understanding of the construct from the perspective of a specific population; to assist in the generation of ideas about the design of scales; to refine a particular measure and its mode of administration; to explore the relative importance, or priority, of different indicators; and to determine the intelligibility or meaningfulness of constituent items.

For the present study, focus groups composed of adults with intellectual disabilities (ID clients), professionals with experience of working with this population (staff), and persons with an adult family member affected by intellectual disabilities (relatives) were formed, to examine the meaning, dimensions, and components, of the quality of life construct for adults with intellectual disabilities. These participants were selected to represent a range of perspectives on the quality of life of the target population, based on personal experience of life quality in relation to the prevailing culture, society and environment, and direct contact with individuals and groups within the population; and to represent those persons ultimately likely to be involved in assessing, or contributing to assessments of, the quality of life of specific individuals.

The methodology employed for the focus groups in the pilot study was based on that used in the original WHOQOL study (WHOQOL Group, 1994b, 1995) with relevant and appropriate adjustments made to support and maximise the contribution of client participants. As recommended by the WHOQOL Group (1993), a standardised approach was taken to all the focus groups, and a detailed protocol was used to guide both the overall shape of the group conversation and the introduction of specific topics.

The focus groups were moderated by the principal researcher, who fulfilled the requirements of having professional credentials, experience of group work, sensitivity to the discussion topic, familiarity with all the group types and knowledge of many individual participants (Morgan and Krueger, 1993). All focus group participants had experience of institutional and/or community based

care and support arrangements, and many had direct involvement in the resettlement and transition of clients within the community cohort of the main study. This experience (in which the principal researcher had also shared) was a particularly important bond for the relatives, the staff and one of the client groups, and in respect of these groups the moderator was 'an insider' (Kitzinger and Barbour, 1999).

Focus Group Types

Each focus group was internally homogeneous in terms of participant type, to provide the opportunity for analysis of differences in perspectives between groups (Morgan, 1997).

With the exception of one group of clients, participants were not recruited by virtue of membership of a concurrent or pre-existing formal group, but were acquainted with other members of their own group through informal, naturally occurring, networks. This was virtually impossible to avoid, given the nature of the study and the circumscribed, but interconnected, nature of the specialty area. Some concerns have been noted in relation to focus groups with social or work related connections, as participants' responses may be biased in terms of shared past experiences, or previous discussions, rather than contemporaneous aspects of the research topic (Krueger, 1994). However, the fact that participants were not strangers conferred some advantages also, including enhanced levels of comfort in discussing the subject matter and increased likelihood of contextually related ideas being generated.

Forty-six people participated in the focus groups. As shown in Table 5.1, 22% were clients with intellectual disabilities, 20% were relatives of people with intellectual disabilities, 26% were qualified staff from a mixture of professional backgrounds, all of whom had significant experience with the client group and 33% were staff in training, specifically trainee clinical psychologists.

Table 5.1: Participants by Focus Group Type

Participant Type	Background	*N*	%
Clients with Intellectual Disabilities	In healthcare, social care and own home	10	21.7
Relatives	ID family person in health and social care	9	19.6
Qualified Staff (mixed professions)	Experienced in working with ID clients	12	26.1
Staff in Training (clinical psychologists)	Contemporaneously on ID placement	15	32.6
		46	100.0

The latter group was an opportunistic addition to the set of focus groups planned originally, and the decision to include these participants was taken in anticipation

of the potential for useful insights into the quality of life of adults with intellectual disabilities being captured by 'fresh eyes' and the counterbalancing effect this might have on the views of the typically older, and possibly world-wearier, relatives and the experienced staff.

From the four participant types, six focus groups were held in all. As shown in Table 5.2, apart from the trainee group, all the focus groups were small. The two client groups were designed as mini focus groups of five participants; one staff group fell into this category also as a result of a late cancellation; and the two remaining groups fell within typical range of focus group composition of 6-10 people (Krueger, 1994; Morgan, 1997).

Table 5.2: Participants by Focus Group

Group	Participants	*N*
1	Staff 1	7
2	Staff 2	5
3	Relatives	9
4	Clients 1	5
5	Clients 2	5
6	Trainee Psychologists	15

Focus Groups 1 and 2 comprised staff with a wide range of generic and specialist experience of people with intellectual disabilities in both hospital and community settings. Staff group one had specialist experience with clients presenting significant challenges to services e.g. those with behavioural problems; while staff group two had specialist experience with so-called 'special needs' clients, i.e. those with severe and profound disabilities.

Focus Group 3 comprised relatives of clients with intellectual disabilities (mostly, but not exclusively, parents), who had experience of both health and social care services, as their family member had formerly resided in a hospital for people with learning disabilities, but now lived in community based residential care.

Focus Groups 4 and 5 comprised clients with intellectual disabilities with a range of dependency and support needs. Client group one had formerly been hospital in-patients, but now lived in a small (NHS managed) house in the local community. Client group two lived in a range of social care settings in the community and attending an advocacy group at a local resource centre. The direct contribution of clients was of particular interest within the study, and the availability of two client focus groups provided the opportunity to compare group output and offered some limited control of data arising from the particular dynamics of one small sample of the population.

Finally, Focus Group 6 comprised a group of postgraduate trainee clinical psychologists approaching the end of their first year of training. All the trainees had received related academic teaching, and all were contemporaneously engaged in supervised clinical practice with clients with intellectual disabilities, in a range of hospital and community settings.

Characteristics of Participants

All participants were requested to provide basic socio-demographic information on a form provided at the end of the focus group session (as shown in A5.1 in Appendix 5). Where necessary, assistance was provided for this task.

Gender and Age

Overall there was an even split between male and female participants. As shown in Table 5.3, the composition of five groups included a gender mix, but one client group was exclusively male. This group of clients resided in a small NHS facility in the community, and reflected the over-representation of men in both NHS facilities and in the intellectual disabilities population (Emerson et al 2001). In contrast, the trainee clinical psychologist group was heavily biased towards female participants, reflecting the contemporary bias of approximately 80% female to 20% male applicants to all UK clinical psychology courses (Clearing House for Postgraduate Course in Clinical Psychology statistics for 2001).

Table 5.3: Participants by Gender and Age

Group	Participants	Male		Female		Age Range
		N	%	*N*	%	
1	Staff 1	5	71.4	2	28.6	35-49
2	Staff 2	3	60.0	2	40.0	35-44
3	Relatives	4	44.4	5	55.6	60-75+
4	Clients 1	5	100.0	0	0	25-44
5	Clients 2	3	60.0	2	40.0	25-54
6	Trainee Psychologists	3	20.0	12	80.0	20-39
	All Groups	23	50.0	23	50.0	20-75+

In deference to possible participant sensitivities (and in an attempt to maximise information provided) data on age were collected in 5-year age bandings. As shown in Table 5.3, the age of participants ranged from 20 to over 75 years. Unsurprisingly, the relatives of adults with intellectual disabilities were the oldest group; the qualified staff were predominantly in the middle age ranges; and some of the youngest participants were the clients and the trainee psychologists, the age ranges of which groups overlapped considerably.

Marital Status

Within each focus group type (clients, relatives, qualified staff and trainees), there were both married and single participants. As shown in Table 5.4, overall 39% of participants were single, 52% were married or living as married, and 9% were separated or divorced.

Table 5.4: Participants by Marital Status

Group	Participants	*N*	Single	Married / Cohabiting	Separated / Divorced
1	Staff 1	7	1	6	0
2	Staff 2	5	0	2	3
3	Relatives	9	1	8	0
4	Clients 1	5	5	0	0
5	Clients 2	5	3	2	0
6	Trainee Psychologists	15	8	6	1
	All Groups *N*	46	18	24	4
	%		39.1	52.2	8.7

Children

Also within each focus group type there were participants with and without children. As shown in Table 5.5, overall 39% of participants had children (of which 22% had 1-2; 15% had 3-4; and 2% had 5 or more children) and 61% of participants did not have children.

Table 5.5: Participants by Number of Children

Group	Participants	*N*	Number of Children			
			None	1-2	3-4	5+
1	Staff 1	7	2	3	2	0
2	Staff 2	5	1	3	1	0
3	Relatives	9	2	3	3	1
4	Clients 1	5	5	0	0	0
5	Clients 2	5	4	1	0	0
6	Trainee Psychologists	15	14	0	1	0
	All Groups *N*	46	28	10	7	1
	%		60.9	21.7	15.2	2.2

Residential Location

The majority of the participants lived in urban or suburban communities (87%) with only a small proportion (13%) describing their residential area as rural.

Education

The participants' educational background was wide ranging as shown in Table 5.6. Overall 96% of participants responded to this item, of which 23% (all of the clients) had received special education; 7% had attended regular school; 14% had attended college; a further 11% had university education to first-degree level and 46% had postgraduate education (heavily biased by the trainee psychologists who represented ¾ of this group).

Table 5.6: Participants by Highest Level of Education

Group	Participants	*N*	School	College	University	Post-Graduate	Special Education
1	Staff 1	7	1	3	1	2	
2	Staff 2	5		1	3	1	
3	Relatives	9	2	2	1	2	
4	Clients 1	5					5
5	Clients 2	5					5
6	Trainee Psychologists	15				15	
	All Groups *N*	46	3	6	5	20	10
	%		6.8	13.6	11.4	45.5	22.7

Missing cases: relatives group = 2

Employment

As shown in Table 5.7, overall 63% of the participants were employed, 20% were retired and 17% attended local day centres. Self-evidently, all the staff (both qualified and trainees) were employed; and all the relatives (all over 60) were retired. Two clients (20%) had regular paid jobs (representing 7% of the overall employed group) both retail related; and eight clients (80%) attended structured day centre activity programmes.

Table 5.7: Participants by Current Employment Status

Group	Participants	*N*	Employed	Day Centre	Retired
1	Staff 1	7	7		
2	Staff 2	5	5		
3	Relatives	9			9
4	Clients 1	5		5	
5	Clients 2	5	2	3	
6	Trainee Psychologists	15	15		
	All Groups *N*	46	29	8	9
	%		63.0	17.4	19.6

Recruitment and Consent

Participants were recruited to the focus groups by a combination of methods including telephone calls, letters and small introductory meetings.

In all cases, potential participants were provided with standardised information about the research, including information on confidentiality, participant anonymity and the possibility of refusal, and given *at least* 24 hours, but in many cases much longer, to consider whether or not they wished to take part. All those who ultimately agreed to participate were requested to sign an appropriate consent form.

Relatives

As the relatives were all known to the researcher prior to the focus group, they were approached initially by telephone. The purpose of both the main study and the focus group pilot work was explained; the basic methodology of the focus group was described; the project information and consent procedures were outlined; and they were invited to take part. A letter was then sent to each relative (see example A5.2 in Appendix 5) reiterating the information given verbally and confirming the proposed date and time of the group. Enclosed with this letter was the detailed participant information sheet (A5.6 in Appendix 5) and two copies of the participant consent form (A5.7 in Appendix 5), one copy to be returned if, after considering all the information provided, the person wished to proceed with the group, the other copy to be retained for information. Nine relatives were approached, all confirmed their willingness to take part, and all subsequently attended and took part in the focus group discussion.

Staff

The recruitment procedure for qualified staff followed the same pattern (an example of the letter sent to staff is shown at A5.3 in Appendix 5). Eight staff were approached to participate in the first staff focus group and all confirmed their willingness to take part. However, only seven staff subsequently took part in the discussion, as one person was unable to attend on the day. Seven staff were approached to participate in the second staff focus group and all confirmed their willingness to take part. Five staff subsequently took part in the discussion, as two people were unable to attend on the day (one of whom was the non-attendee of the first group, who had asked to be invited a second time).

The twelve staff that attended the focus groups brought together experience from health and social care and settings. They were drawn from a broad range of professional backgrounds including medical, nursing, clinical psychology, speech and language therapy, physiotherapy, art therapy, social work and management. The two staff that were invited, but unable, to attend were from the voluntary sector and a statutory group representing users of the NHS.

Clients

The recruitment procedure for clients followed the same basic principles, and included the same safeguards, as the other groups, but was customised in a number of ways to better meet the needs of the individuals.

Clients were approached initially via the member of staff responsible for the day-to-day management of their service. It was possible to approach this direct manager as the overarching agreement about access to clients within the relevant agencies had already been obtained at chief officer/responsible medical officer level (see Chapter 4). The main advantage of selecting the service manager was that this member of staff had knowledge of their clients, and a relationship of trust existed between them. In a preliminary face-to-face meeting with this staff member, the project was described, and the help that was being sought from clients was outlined. At this meeting, the focus group procedure, including the information and consent stages, was explained in detail and the manager was asked if some clients would be interested in, and have the ability to, take part in the focus group discussions. The service manager was provided with copies of the participant information sheet and the consent form; asked to introduce the subject to clients in general terms; and requested to pass on to the researcher the names of those clients who expressed interest in the project. This procedure was employed to try to avoid a situation in which a client might feel under pressure to acquiesce to a request made directly from the researcher, as it was anticipated that a refusal might be easier in the context of an established staff-client relationship.

A letter reiterating the information given to the clients by their manager was then sent to the clients so identified, confirming the proposed date and time of the group (an example of the letter sent to clients is shown at A5.4 in Appendix 5). A few days later a meeting was held between these clients and the researcher, at which a further full description of the project was given and clients were encouraged to ask questions or raise concerns. The participant information sheet and the consent form were explained in detail and where necessary, the documents were read out and explained section at a time, in language tailored to the particular needs of clients present. It was stressed that each individual could make up their own mind about whether or take part in the focus group, and that no unfavourable consequences would ensue from a decision not to participate. The clients were reminded that their manager also had copies of these documents, so that questions or concerns emerging after the meeting could be discussed or clarified with this staff member. Subsequently, the manager was contacted by telephone to establish if any of the clients had proceeded to give formal consent for participation in the focus group discussion. Six clients expressed initial interest in the first client focus group, and all attended the meeting with the researcher. Five of these clients subsequently took part in the focus group discussion, and one person chose to decline. A further five clients expressed initial interest in the second client focus group, all of whom met with the researcher and then subsequently took part in the group.

The ten clients who participated in the focus groups were in receipt of NHS and/or social care services. Some had experience of supported accommodation or day care services provided by the statutory or voluntary agencies; and some had experience of a range of visiting support services.

Trainee Psychologists

The sixth focus group was serendipitous, but once again the core components of participant recruitment were followed. The researcher was asked to contribute to a seminar on the quality of life of adults with intellectual disabilities for first year trainee clinical psychologists. This invitation was prompted by the relevant academic module co-ordinator's knowledge of the current research. The outline seminar programme that was requested included a discussion of the facets of quality of life important to people with intellectual disabilities. A suitable programme was drawn up and circulated to trainees prior to the session. Additionally, a letter was sent to each trainee inviting them to participate in this discussion within the context of a focus group format, from which ideas generated might be included in the research (see letter at A5.5 in Appendix 5). Enclosed with this letter were copies of the detailed participant information sheet and consent form. Sixteen trainees were approached to participate in this way, 15 subsequently gave consent and took part in the focus group, and one person missed the session due to illness.

The 15 trainee clinical psychologists who participated in the focus group were based in locations across seven Scottish regions, in which they were completing a period of supervised practice in relation to clients with intellectual disabilities in both health and social care settings.

Procedure

The main procedural elements of the focus group design were common to all group types. However, minor adjustments were made in relation to the clients (to adapt the format to assist and support participation) and the trainee psychologists (in relation to the context and constraints of this group). All groups were scheduled for a maximum of two hours; all were held in suitably comfortable, distraction-free settings; and considerable effort was directed at creating a relaxed atmosphere, to foster the contributions of all participants.

Within each group, the specific terminology used for the target population varied in line with the common parlance of group members. Although the moderator tended to use the term intellectual disabilities, many staff used the term learning disabilities, some clients preferred learning difficulties, and some relatives were more comfortable with the older term, mental handicap.

Pre-session

Before each focus group, a check was made to ensure that all participants had signed and returned a consent form. Refreshments were available prior to the commencement of each group, providing an opportunity for a brief period of informal social interaction between participants on arrival. This was designed to put people at ease (Krueger 1994) and help promote openness in the more task-orientated interaction required within the structured group setting. Also, participants were offered the opportunity to clarify any last minute points about the research purpose, group procedure, or use of the outcome data, in order to maximise their comfort with the task.

Welcome, introduction and ground rules

At the start of each group, participants were welcomed and the moderator made a brief opening statement providing an introduction to the main and pilot studies, outlining the rationale for the focus groups and describing the methodology, setting the scene for the discussion topic, and identifying the aims and objectives of the group.

Particular emphasis was given to the desire to obtain a wide range of perspectives on the dimensions that might be important in assessing the quality of life of people with intellectual disabilities, and the specific facets that contribute to an individual's perception of their life quality. It was stressed that there were no 'right' or 'wrong' suggestions in this regard; that the task was to generate as many contributions as possible, all of which would be valued; and that the aim was to hear from everyone, in terms of both ideas and 'stories' which might exemplify various issues. However, participants were encouraged to remain focussed on the generality of the target issues and to avoid over reference to specific individuals with intellectual disabilities known to them.

As the discussions were to be audio taped, participants were requested to follow basic 'ground rules' for taped discussion (contributing one at a time, avoiding side conversations etc).

Although the participants in each group knew one-another and the moderator, the usual opening round of self-introduction was made to 'break the ice' by getting each participant to speak early in the procedure. This underlined the commonalities of participants that formed the basis for information sharing and exchange of ideas, and for the benefit of the tape.

Starter question and introductory task

Participants were asked to reflect on their past experience of the topic of the quality of life of adults with intellectual disabilities, to consider the question of what contributes most to the quality of life of such individuals, and to make a list

of some of the key themes that came to mind. Group members were requested to complete this task on an individual basis initially, as group discussion of the themes generated would follow. A few minutes were given for the task and a prepared form (A5.8 in Appendix 5) was provided for each person to record up to 10 (or more if desired) quality of life themes in section A.

This task was designed as a starter question and an orientation exercise: to raise participants' awareness of their own views on the topic (discouraging 'group think') and engage their individual commitment; and to provide a preparation for each person's first contribution to the group discussion.

Participants were then invited to share their key themes one or two at a time, going round the group until all the lists were exhausted. The extent of consensus and/or diversity was then discussed, and an opportunity for the generation of additional themes was provided, as participants own views resonated with that of other group members to produce new insights. As the discussion of the introductory task progressed, the moderator made a personal note of how the emerging quality of life themes linked with the WHOQOL facets, in order that some of the related quality of life facets not yet mentioned could be introduced and discussed at appropriate points in the flow of discussion.

Key question one: relevance of WHOQOL facets

Each participant was then provided with a laminated copy of the focus group Topic Guide (A5.9 in Appendix 5) on which the four domains and twenty-four facets of the WHOQOL-BREF could be seen simultaneously. The description of two WHOQOL facets was augmented for the purpose of the focus group in order to increase the salience for adults with intellectual disabilities (shown italicised in the appended Topic Guide). Work capacity was augmented in terms of supported employment and structured activities in which many people with intellectual disabilities participate in place of paid employment; and sexual activity was expanded to include intimate relationships (short of sex), physical closeness and warmth, in order to increase general applicability for those with profound or multiple disabilities.

Participants were invited to consider the full list of WHOQOL facets and discuss them in terms of their relevance to the quality of life of adults with intellectual disabilities.

Key question two: additional themes

Once the relevance (or otherwise) of each of the WHOQOL facets was discussed, participants were invited to consider whether there were any additional quality of life themes, not generated by the introductory task or contained in the facets on the Topic Guide, but which had been prompted by the discussion or stimulated by participants interactions.

Key question three: applicability of WHOQOL-BREF items

The WHOQOL-BREF was introduced and the background to the development of the WHOQOL measures of quality of life was described. The constituent items of the WHOQOL-BREF were then displayed (suitably enlarged) on an overhead projector. The potential use of the instrument in the present study was outlined and participants were asked to consider each item in terms of the general applicability for adults with intellectual disabilities, and the suitability for administration to this population in the current format, with specific reference to issues of intelligibility and potential ambiguities. Participants were invited to make informal suggestions about appropriate re-wording of any item considered problematic for the client group also.

Final question and closure task

Firstly, participants were asked to review the list of quality of life themes drawn up individually during the introductory task, and invited to make additions to their lists (if desired) in the light of the focus group discussion, noting these in section B of the record form (A5.8 in Appendix 5). This provided participants with the opportunity to review their spontaneously generated themes previously noted in section A, together with any themes prompted by the group discussion which had particular resonance for them, in undertaking the closure task.

Subsequently, each person was asked to consider their personal opinion of which themes ranked as the top three facets of quality of life for adults with intellectual disabilities, bearing in mind all the issues discussed, and add these to section C of the record form. This task was designed as a closure exercise: to enable participants to reflect back on the themes mentioned in the focus group discussion; to stimulate consideration of both their own contributions and those of other group members; and to encourage each person to make an individual determination about the relative importance of some of the key quality of life themes, in terms of a final statement. Participants were then invited to share their top three themes with the group and once again the extent of consensus and/or diversity was discussed.

Additional thoughts and final contributions

Participants were provided with a final opportunity to contribute any additional thoughts on the discussion topic, and a last request was made to consider if anything had been missed.

Summing up, overview and expression of thanks

The moderator provided a brief summary of the key points that had emerged from the focus group exercises and discussion and checked both the clarity and adequacy of this overview with the group.

Finally, participants were thanked for taking part in the focus group discussion and for making so many useful contributions. (A few days after each focus group, a short letter of thanks was sent to each participant also, examples of which are shown in A5.10 - A5.12 in Appendix 5.)

Post-session

At the end of the group, participants were requested to provide basic socio-demographic information by completing a short form (A5.1 in Appendix 5).

Procedural Variations

The relatives' focus group, and both focus groups for qualified staff, all followed the procedure outlined above. The procedural variations made to the clients' and the trainee psychologists' focus groups are described below.

Clients

The procedural variation in the clients' focus groups arose from issues related to their characteristics. Firstly, although the clients had adequate verbal skills, consistent with being able to express their views and contribute to the discussion, it was evident before the group took place that many lacked the level of literacy necessary to complete the form on which quality of life themes were recorded in the introductory and final tasks. A number of ways of overcoming this problem were considered. For example, each client could have been provided with a small tape recorder and shown how to use this as a personal memo (rejected as some individuals would have required relevant skills training prior to the focus group, and performance may not have been reliable); the moderator could have provided assistance to complete the form during the group (rejected as it would be time consuming and the attention of other group members may not have remained focussed); or each client could have been assigned a 'buddy' to provide assistance with the form (rejected because of the potential impact on group dynamics of doubling the numbers).

From the meetings with clients during the recruitment procedure, it was apparent also that some clients were reticent when 'under the spotlight' and rather more open and comfortable in the company of one or two other clients. Therefore the focus group procedure was modified so that each group was subdivided, into one mini-group of two clients and one mini-group of three clients, for the purpose of the two tasks; and an assistant moderator (a member of staff known to the clients) was introduced. The clients were invited to generate the quality of life themes in these mini-groups and the moderator and assistant moderator provided assistance to write down the quality of life themes. The assistant moderator for each focus group was fully briefed on the task and the necessary limitations of their role (as a communication channel only) prior to the group session.

Trainee Psychologists

The context and serendipitous nature of the trainee psychologists' focus group (placed within an academic seminar) shaped its procedural variation. The number of participants and the large 'horseshoe' seating plan dictated by this, militated against audio taping the proceedings, and constrained some elements of the focus group discussion. Therefore, audiotaping was not undertaken; and a decision was made to emphasis the two written tasks and the discussion in relation to key questions one and two (generation of quality of life facets and discussion of WHOQOL facets).

Venues for Groups

The relatives', qualified staff and trainee psychologists' focus groups were held on central University/NHS sites. In contrast, the clients' focus groups were convened in settings with which the particular sets of clients were familiar and comfortable; in one case this was a residential setting, and in the other a local resource centre.

Focus Group Discussion Notes and Transcripts

The two focus groups for qualified staff and the relatives' focus group were successfully audio taped and fully transcribed for analysis.

The two clients' focus groups were audio taped also, but with much less success, as the clients found it more difficult to observe the ground rules for taping. A trial run was held prior to the start of each focus group, during which signs in common usage were practiced to facilitate the discussion process. An agreed 'stop' sign (hand pointing up, palm facing outwards) was employed to represent 'please don't interrupt, I haven't finished' and an agreed 'me next' sign (arm slightly outstretched, index finger of hand raised) was used to indicate 'I have something to say'. These worked well within the confines of a brief rehearsal, but in the heat of general enthusiasm for the group, and the desire to contribute and be heard, ground rule compliance fell drastically short of that required for adequate tape transcription. Therefore, a list of the themes noted from the client group discussions was produced instead.

The discussion notes from the clients' focus groups are presented in A5.20 (clients group one) and A5.21 (clients group two); and the full transcripts of the staff and relatives focus groups are presented in A5.22 (staff group one), A5.23 (staff group two) and A5.24 (relatives) in Appendix 5.

5.3 Quality of Life Themes

The quality of life themes generated by the focus groups were collated from the record forms (see Appendix 5.8) used for the individual tasks, and from simple analysis of the transcripts and discussion notes.

The language used to express themes was preserved as far as possible. Grouping or other means of classification of emergent themes was limited at this stage (and coding was avoided) in order to preserve the integrity of themes for subsequent comparison with the facets of the WHOQOL-BREF.

Identification of Themes

The nature of the individual task record form (providing an enumerated list of themes considered by participants to be important to the quality of life of adults with intellectual disabilities) simplified the initial identification of themes generated by individuals within each group. For each focus group, these quality of life themes were collated into a set of individually generated themes, which was compared with the relevant focus transcript, in order to identify any additional themes generated within the setting of the group discussion.

The principal researcher undertook this procedure initially. Subsequently, two graduate research assistants reviewed the individual and group themes, cross-checking the results against the focus group transcripts. In order to promote reliability[1], a consensus approach was taken to producing a final set of themes within and across groups.

Emergent Themes

A total of fifty-nine quality of life themes were thus identified, many of which were mentioned several times, both within and between groups. The themes generated by participants in each of the focus groups are presented in full in Tables A5.13 – A5.18 in Appendix 5. A summary of the overall frequency of themes by focus group is presented in Table A5.19, also in Appendix 5.

Consensus and Diversity

Five out of six focus groups engaged in both individual tasks and group discussion. In each of these, the majority (on average 65%) of the quality of life

[1] The issue of reliability in relation to this component of the pilot study could have been approached in a different way e.g. by using a 'blind' procedure to identify themes; calculating and reporting inter-rater reliability; and defining a 'rater-agreed' set of themes. However, the more discursive and iterative approach adopted had the advantage of promoting breadth and richness in terms of the number and variety of themes identified, which met the objectives of this stage of the research design more effectively.

themes were generated spontaneously, in the setting of the individual tasks. This was unsurprising in view of the topic relevance, and given (variously) the participants' background knowledge, experience and skills. However, a significant proportion of additional themes (on average 35%) were generated as a result of the interaction between group members in discussion, supporting the combined methodology as an effective (although more time consuming) design.

The balance of individually generated and group discussion prompted themes are summarised for each focus group in Table 5.8.

Table 5.8: Proportion of Themes Generated Individually and in Group Discussion

Group	Participants	*N*	Quality of Life Themes Generated				
			Individual		Group		Total
			N	%	*N*	%	*N*
1	Staff 1	7	32	80.0	8	20.0	40
2	Staff 2	5	22	50.0	22	50.0	44
3	Relatives	9	28	70.0	12	30.0	40
4	Clients 1	5	12	63.2	7	36.8	19
5	Clients 2	5	19	61.3	12	38.7	31
6	Trainee Psychologists	15	40	100.0	-	-	40

The groups comprising staff, trainee psychologists and relatives each generated approximately 40 themes. The two client groups generated slightly fewer themes overall, but produced 50 - 75% of the output of other groups, thus clearly demonstrating their capacity to engage in the focus group work.

No single group mentioned all 59 themes. As shown in Table 5.9, five groups (including staff, relatives, and clients) mentioned over half of the themes, either as individual task-related contributions, or within the overall group discussion, and one group (clients) mentioned fewer than half of the themes.

Table 5.9: Proportion of Total Themes Generated by Group

Group	Participants	*N*	Quality of Life Themes Generated					
			Individual		Group		Total	
			N	%	*N*	%	*N*	%
1	Staff 1	7	32	54.2	8	13.6	40	67.8
2	Staff 2	5	22	37.3	22	37.3	44	74.6
3	Relatives	9	28	47.5	12	20.3	40	67.8
4	Clients 1	5	12	20.3	7	11.9	19	32.2
5	Clients 2	5	19	32.2	12	20.3	31	52.5
6	Trainee Psychologists	15	40	67.8	0	0	40	67.8
	Totals	46					(*N* = 59)	

Three of the groups, (staff group two, relatives and clients' group two) which identified over half of the total themes generated, were the most productive in the group discussion also, generating at least a further 20% of themes in this setting.

On average, each theme was mentioned approximately seven times (range 1-29) the equivalent of just over once per group. However, as shown in Table 5.10, only ten themes (17%) were identified by all six of the groups. A further ten themes (17%) were mentioned in five groups; thirteen themes (22%) were discussed in four groups; nine themes (15%) were mentioned in three groups; eight themes (14%) were identified by two groups; and nine themes (15%) were noted by one group only.

Table 5.10: Proportion of Themes Identified by Group

Groups	Themes Identified	
	N	%
6	10	16.9
5	10	16.9
4	13	22.0
3	9	15.3
2	8	13.6
1	9	15.3
	59	100.0

This suggested that the balance of participant type and format variation (task and discussion) had produced a useful range of consensus and diversity in relation to the quality of life themes across the six groups.

Frequency

The frequency[2] with which themes were mentioned by individuals[3] and/or by groups varied considerably. A full analysis of the frequency of themes by focus group is presented in Table A5.19 in Appendix 5. A summary of the highest frequency themes is presented in Table 5.11. This shows the most frequently mentioned themes (those ranked 1-20), together with the occurrence rate (as a percentage of total participants) and rank of each.

The highest frequency theme overall was 'personal relationships' which was mentioned by 63% of participants representing all group types. However, the

[2] Total theme frequency for groups was calculated by summing the number of times a theme was mentioned by individuals (within the task framework), then adding any additional themes generated as part of the group discussion.

[3] Client themes emerged in the format of individual mini-groups, and subsequently the combined group. However, for the purpose of comparison of frequencies between groups, mini-group frequencies were treated in the same way as individual frequencies for other groups.

breakdown by participant type indicates that this theme was mentioned most often by staff and least often by relatives.

Similarly, the second highest frequency theme was 'choice' which was identified by 46% of participants. This was mentioned in discussion by both of the client groups and around two thirds of the staff, but identified by only one fifth of relatives.

Table 5.11: Summary of High Frequency Themes - All Groups (N = 46)

Themes / Quality of Life Facets	Frequency	% (*N*)	Rank
Personal relationships/friendships - good, stable, meaningful	29	63.0	1
Choice (meaningful, informed, appropriate)	21	45.7	2
Home - pleasant, comfortable, happy, small group/individual	20	43.5	3
Leisure/social activities (varied)	17	37.0	4
High quality social/residential care	15	32.6	5
Day activities/services (to develop/promote skills)	14	30.4	6 =
Employment/occupation	14	30.4	6 =
Financial security/decent income/personal money	14	30.4	6 =
Health (physical & psychological)	13	28.3	9 =
Independence (general) / Freedom	13	28.3	9 =
Freedom of expression/communication of wishes	11	23.9	11
Continuity of support (stability, consistency)	10	21.7	12 =
High quality health care	10	21.7	12 =
Independence in ADL (to maximum extent)	10	21.7	12 =
Social acceptance (by local community)	10	21.7	12 =
Social support (family, friends, neighbours)	10	21.7	12 =
Use of normal community/generic facilities resources	10	21.7	12 =
Privacy, personal space	9	19.6	18 =
Respect, as valued (normal) citizens, individuals	9	19.6	18 =
Environment, space, attractive surroundings	8	17.4	20 =
High quality support staff (residential, day, visiting)	8	17.4	20 =
Intimate relationships	8	17.4	20 =

The third highest frequency theme was 'home' which was mentioned by 44% of participants. This was identified by both client mini-groups in relation to client group one, mentioned in the full group discussion by client group two, and identified by four fifths of staff group two (biased towards experience of work with severe and profound disabilities); but was only mentioned by half of the other staff groups (including the trainees) and one third of the relatives.

In contrast, 'high quality social/residential care', ranked fifth overall and mentioned by 33% of participants, and 'continuity of support', ranked twelfth and mentioned by 22% of participants, were each identified by approximately half of the relatives (and accounted for the highest ranking relatives' themes).

This suggested that the influence of viewpoint played a significant part in the contributions of each group. At the forefront of relatives minds may have been basic, practical issues of care and support (all the more salient as a result of the recent experience of resettlement in connection with their family member).

Possibly with the benefit of greater professional distance, staff were more likely to identify the rather more ideologically driven psychosocial issues of relationships and choice.

Paradoxically, neither of the clients' groups mentioned these social/residential care and support themes. Three out of four client mini-groups mentioned leisure activities (rank four), and employment (rank seven), and all four mini-groups identified day activities/services (rank six) as contributing to their quality of life. In respect of the latter themes, staff group two did not identify leisure activities or day services within the individual tasks, but only generated the theme in full group discussion. No relative mentioned employment in any context.

In respect of low frequency themes, those identified by clients were of particular interest. Of those identified only once or twice (eight themes in each case) only clients identified two nurturing roles 'helping others' and 'looking after pets'; only clients mentioned 'not being called names' and 'not being labelled'; and only clients and one staff group noted the importance to quality of life of 'non-discrimination/positive profile'.

Finally, within the middle ranking themes, none of the relatives identified 'advocacy' as being relevant to the quality of life of adults with intellectual disabilities; and despite its central role in many services, none of the qualified staff generated this theme in the individual task, although both groups identified advocacy in the group setting. However, three out of four client mini-groups mentioned this issue, as did two trainee psychologists.

Importance

The importance attached to a particular quality of life theme by an individual participant, or a focus group type, cannot be inferred from either its frequency, or from the proportion of related discussion time (Morgan, 1997). The final task in the focus group procedure was designed to distinguish what participants regarded as the three most important quality of life themes, by asking the question directly and unambiguously.

Simple importance scores were derived by assigning three points to the most important theme (rank 1), two points to the second most important theme (rank 2) and one point to the third most important theme (rank 3) as identified by individual participants. These scores were then aggregated within focus groups, across focus group types (by combining the two staff groups and the two client groups), and for all groups.

Table 5.12 shows the three themes that emerged as most important across all groups.

Table 5.12: Summary of High Importance Themes – All Groups (N = 46)

Quality of Life Themes	Rank	Score
Personal relationships/friendships - good, stable, meaningful	1	39
Home - pleasant, comfortable, happy, small group/individual	2	24
Choice (meaningful, informed, appropriate)	3	19

Overall, 'personal relationships' emerged as the most important theme. The second most important theme was 'home' and the third most important was 'choice'. In this instance, these *were* the three highest frequency themes overall also, but with positions 2 and 3 reversed.

However, the rankings of these themes across all participants were not reflected uniformly in the separate participant types. As shown in Table 5.13, clients, staff, and trainee psychologists considered 'personal relationships' the most important theme; but for relatives it was 'home' (ranked second by staff and third by clients).

Table 5.13: High Importance Themes by Participant Type

Participant Type	*N*	Quality of Life Themes	Rank	Score
Staff	12	Personal relationships/friendships - good, stable, meaningful	1	14
		Home - pleasant, comfortable, happy, small group/individual	2	7
		High quality health care	3	7
Relatives	9	Home - pleasant, comfortable, happy, small group/individual	1	11
		High quality support staff (residential, day, visiting)	2	7
		Continuity of support (stability, consistency)	3	5
Clients	10	Personal relationships/friendships - good, stable, meaningful	1	3
		Social support (family, friends, neighbours)	2	3
		Home - pleasant, comfortable, happy, small group/individual	3	2
Trainee Psychologists	15	Personal relationships/friendships - good, stable, meaningful	1	21
		Choice (meaningful, informed, appropriate)	2	11
		Good health (physical & psychological)	3	10

'Choice' was the second ranked theme for the trainee psychologists, but did not make the top three in respect of any of the other participant groups. (The third ranked position of this theme overall being accounted for by the disproportionate number of trainees compared with other participants).

Health related themes emerged as the third ranked theme by both qualified staff and trainees, perhaps reflecting their experiential bias; but various support related themes were ranked amongst the top three themes by both relatives and clients.

Relatives ranked 'high quality support staff' and 'continuity of support' as the second and third most important themes; and clients identified the less formal 'social support' as the second most important theme.

Relevance of WHOQOL Facets

The themes that emerged from the focus group discussions included almost all quality of life facets measured by the WHOQOL. Only four facets within the four main domains of the WHOQOL failed to emerge spontaneously, either in response to the individual tasks, or within the context of the group discussions: energy and sleep from the physical domain; and thinking and negative feelings from the psychological domain. However, when prompted by examination of the Topic Guide that displayed the WHOQOL facets, all six focus groups confirmed that all of the facets, including these four, were important to the quality of life of adults with intellectual disabilities. Therefore, no WHOQOL facet was discarded from consideration for this population on the grounds of relevance.

Correspondence of Themes to WHOQOL Domains and Facets

Some of the themes generated by the focus groups reflected expressions, or illustrations, of higher order or related quality of life themes. Theme classification or reduction had been avoided thus far (except for the aggregation of different expressions of the same theme) and therefore, the full fifty-nine emergent themes were compared with the twenty-six facets of the WHOQOL-BREF to establish the correspondence of themes to the quality of life facet definitions, as provided by the Draft WHOQOL User Manual (WHO, 1998).

The principal researcher undertook this comparison initially. Subsequently, a graduate research assistant repeated the procedure independently. In order to promote reliability, a consensus approach was taken to producing the final taxonomy of themes and determining which (if any) failed to match an existing WHOQOL facet.

Table 5.14: Correspondence of Focus Group Themes to WHOQOL Domains

WHOQOL Domain	WHOQOL Facet	Focus Group Theme
General	2	1
Physical	7	7
Psychological	6	4
Social Relationships	3	5
Environment	8	25
Included themes	26	42
Additional themes	0	17

Table 5.15: Correspondence of Focus Group Themes to WHOQOL Facets

WHOQOL Domains / Facets	Focus Group Themes
GENERAL	
Overall quality of Life	
General health	Health (physical & psychological)
PHYSICAL	
Pain and discomfort	Physical comfort
Dependence on medication and medical aids	Specialist medical equipment, aids etc
Energy and fatigue	
Mobility	Mobility
Sleep and rest	
Activities of daily living	Independence in ADL (to maximum extent)
Work capacity	Day activities/services (to develop/promote skills)
	Education (FE courses etc)
	Employment/occupation
PSYCHOLOGICAL	
Positive feelings	Emotional security
Spirituality, religion, personal beliefs	Meaningful life, spiritual expression
Thinking, learning, memory and concentration	
Body image and appearance	Body image, self concept, appearance
Self esteem	Self esteem, feeling valued
Negative feelings	
SOCIAL RELATIONSHIPS	
Personal relationships	Personal relationships/friendships - good, stable, meaningful
	Helping others, looking after others (e.g. family)
	Age appropriate relationships, activities
Sexual activity	Intimate relationships
Social support	Social support (family, friends, neighbours)
ENVIRONMENT	
Freedom, physical safety and security	Safety - general and personal
Physical environment (pollution, noise, traffic, climate)	Environment, space, attractive surroundings
	Calm, peace and quiet, not noisy
	Use of normal community/generic facilities resources
Financial resources	Financial security/decent income/personal money
Opportunities for acquiring new information and skills	Information (accessible, plain English, people to explain)
	New experiences (with support if required)
Participation in/opportunities for recreation and leisure activities	Leisure/social activities (varied)
	Holidays
	Celebration of special days (birthdays etc)
	Pets (looking after)
Home environment	Home - pleasant, comfortable, happy, small group/individual
	Part of community - integration
	Own room, personalised
	Privacy, personal space
	Personal belongings, own possessions, own clothes
	Good food
	Cigarettes (if desired)
Health and social care: accessibility, quality	High quality health care
	Access to specialist services (when needed)
	High quality social/residential care
	High quality support staff (residential, day, visiting)
	Continuity of support (stability, consistency)
	Care review/management (plus involvement of relatives)
Transport	Transport (minibus, buses, self-travel)

As shown in Table 5.14, 42 of the 59 themes (71%) identified by the focus groups could be mapped directly onto the WHOQOL domains and general facets. Of the matching themes, seven corresponded with facets in the physical domain; four were associated with facets in the psychological domain; five linked to the social relationships domain; 25 mapped onto the environment domain; and one further theme related to the general health facet. The detailed correspondence between the 42 quality of life themes and the 26 WHOQOL facets is presented in full in Table 5.15.

The bias in favour of themes linked to the environment domain may be a reflection of the relatively greater ease with which participants generated examples of concrete, tangible quality of life themes (e.g. leisure activities, financial security, own room) compared with more abstract themes which were not mentioned in the groups (e.g. energy, thinking, negative feelings); but also suggests that, overall, more consideration was given to the *conditions of life* for people with intellectual disabilities rather than their *experience of life*.

This objective-subjective division was particularly apparent in relation to some of the themes generated by the ID clients (but not other participants) that did not correspond to WHOQOL facets, but fell within the set of additional themes discussed in the next section.

Additional Quality of Life Themes

For 17 (29%) of the 59 themes, it was difficult to identify a corresponding or related WHOQOL facet.

Table 5.16: Additional Themes by Focus Group and Frequency

Additional Themes / Quality of Life Facets	SG1 (*N* = 7)	SG2 (*N* = 5)	RG (*N* = 9)	CG1 (*N* = 5)	CG2 (*N* = 5)	TG (*N* = 15)	Total (*N* = 46)
Choice (meaningful, informed, appropriate)	5	3	2	1	1	9	21
Independence (general) / Freedom	1	1	1	1	1	8	13
Freedom of expression/communication of wishes	2					9	11
Social acceptance (by local community)	1	2	1			6	10
Respect, as valued (normal) citizens, individuals	2	3	1		1	2	9
Advocacy / Rights (self, citizen, rights group, council)	1	1		1	2	2	7
Control of life	2			1		2	5
Equal opportunities (e.g. to do things)	1	1	2				4
Structure to life, predictability, routine	1		1	1	1		4
Non-judgemental support	1		1			1	3
Expectation of being responsible	1					1	2
Non discrimination, positive profile		1			1		2
Not being labelled		1			1		2
Dignity			1				1
Not being called names					1		1
Not being laughed at		1					1
Victimisation		1					1

Black: individual theme frequencies Red: group theme frequencies Blue: Total frequencies

These additional themes, ordered by theme frequency, are presented in Table 5.16. Every focus group yielded additional themes in the context of either individual tasks or group discussion. Each additional theme was mentioned approximately six times (range 1-21), the equivalent of once per group. However, only two themes (12%) were identified by all six groups; and most themes were identified by between two and three groups only. Clients themselves were the source of nine of the additional themes (53%); staff identified 15 additional themes (88%); relatives mentioned eight (47%); and trainee psychologists noted nine (53%).

The focus group records provided useful illustrations of the form and/or context in which the additional themes emerged.

Choice

This theme was raised in all six focus groups. Nineteen participants in four groups mentioned choice in relation to the individual tasks and the remaining two groups (both client groups) raised the issue in the group discussion. Examples of exchanges on this theme from the staff and relatives groups included:

Quote 1:

S11 *Meaningful choice as much as possible...*
S10 *Informed as well...informed choice.*

Quote 2:

R4 *I have got freedom of choice.*
R7 *Yes, I have got freedom of choices*

Clients mentioned choice in relation to everyday practical issues like *'having a long lie'* or being able to *'do your own thing'*. Similarly, one trainee psychologist raised the issue of *'accepting their choices – even when you think they are different to what you think is best'* while another mentioned *'choices that are appropriate'*.

Independence/Freedom

This theme was raised in all six focus groups. Twelve participants in five groups mentioned independence in relation to the individual tasks and one group (the relatives) raised the issue in the group discussion. Examples of this theme from the staff and relatives groups included:

Quote 3:

S10 *I have put to be as independent as possible within their daily life...as independent as that individual can be...they have to have some meaning to what they do.*

Quote 4:

S7 *It is important to maximise their independence. I think that is a training issue for other providers. The tendency is to do everything that they were able to do before, and to do it for them.*

Quote 5:

R3 *What I have noticed with some of the women and men that are able...they are more independent...I've seen them locally and I am amazed...this personality is coming over...this is a wonderful thing...*

Once again, clients mentioned this theme in relation to everyday practical issues like *'making your own tea or coffee'* or *'living on your own'* and *'having a key for the door'*. Trainee psychologists tended to raise the issue of independence and freedom in relation to both domestic and daytime activities, for example *'to be independent - to do what [they] want when [they] want - within the confines of not putting themselves at risk'*.

Freedom of Expression/Communication

This theme was mentioned by eleven participants in two groups (one staff group and the trainee psychologists group), all within the context of the individual tasks. An example from the staff group included the following exchange:

Quote 6:

S3 *Being able to communicate their wishes...*
S4 *Appropriate support when needed.*

The trainee psychologists mentioned the importance of *'effective methods of communication'; 'voicing opinions and seeing actions being taken'; 'listening to the client';* and *'being able to get their ideas/thoughts across and be listened to'*.

Social Acceptance

Ten participants in four groups (both staff groups, relatives and trainees) mentioned social acceptance in relation to the individual tasks. Examples of this theme from the staff and relatives groups included:

Quote 7:

S8 *I think being accepted is very important...by the local community...By that I don't mean a county or a town...I mean by the actual 6 or 12 neighbours in that area...I think that is most important...because if you don't get that from the very start, then I think life for people with learning disabilities in the community will be quite hellish...*

Quote 8:

R7 *It's this feeling of being part of the community. It's not just the community looking after them; it's being part of the community and helping to look after one another...*

Quote 9:

R3 *I also think they are accepted by the community...in actually going to live in the community and that has been a success...going into the community and living there has been amazing.*
R1 *Being part of it...*
R9 *I certainly think there is a greater understanding now...and a greater acceptance than ever there was before...*

The trainee psychologists mentioned social acceptance in relation to being *'accepted as everyone else is in society'.*

Respect

This theme was mentioned by nine participants in five groups, all within the context of the individual tasks. For example, from the relatives and staff groups:

Quote 10:

R3 *Respect for them as individuals*

Quote 11:

S1 *When I was thinking of respect from other people, I was connecting that with self-esteem. Certainly a lot of the clients I work with...lack self esteem...I think that all comes from the way other people have treated them in the past...it's important to them.*

Clients mentioned their desire *'to be treated with respect'* in terms of their interactions with staff and other people also. Trainee psychologists noted the need for *'unconditional positive regard – love and respect'.*

Dignity

A relative generated this theme during the individual task at the start of the focus group.

Quote 12:

R2 *Did we say dignity?*
MOD *We did say respect...*
R4 *Dignity is the same*

Although this theme was mentioned directly on one occasion only, it was implicit in much of the discussion (particularly in connection with 'respect') and in many of the 'stories' told by staff and relatives to illustrate aspects of the quality of life of adults with intellectual disabilities (or sometimes the perceived lack of this).

Advocacy

Staff, both clients' groups, and the trainee psychologists mentioned this theme, either in discussion or as part of the individual task. Staff mentioned advocacy specifically in terms of a 'service watchdog' role:

> *Quote: 13*
>
> *...certainly my experience of working with some of the people with learning disability who challenge services, is that the ones who have strong advocates, or strong parents, or somebody there who is independent, who isn't either the service provider or the professional consultant, tend to get a more balanced and even service. It has been very useful for someone to be independently looking at the service the client receives...and ensuring that...or pointing out if things are inadequate.*

Some clients had previous or contemporaneous experience of the impact of self or citizen advocacy, either having been matched with an individual advocate, or in terms of membership of an advocacy group. Typically, they spoke about this theme in very personal terms: *'speaking up for yourself'*; needing *'support [for this] from staff and volunteers'*; being part of *'the members council'*; and having *'visits from [my] advocate'*.

Similarly, trainee psychologists mentioned advocacy in relation to *'awareness of rights and ability to exercise them'* and the need for *'advocating abilities via themselves or an advocate'*.

Control of Life

Staff, trainee psychologists and clients mentioned this theme. An example of this from one of the staff included:

> *Quote 14:*
>
> *S1* *I certainly think that when I put 'control of your life', that was one of the things I was thinking about because I have become very aware of how quite a lot of people are very dependent on somebody going out with them into the community now. I know we talked about how people can wander round the hospital, and I must admit that I was one of the folks who thought that that was not really quality of life. But I am beginning to rethink that now, realising that there was a certain amount of freedom, at least being able to have some control when you went out. Now you always...a lot of the time, you have to say 'can I go?'*

Clients mentioned the importance of *'being able to do your own thing'*; and the trainee psychologists noted the related issues of *'having choice and control over where you go and what you do'* and being *'able to make decisions...e.g. daily and life decisions'*.

Equal Opportunities

This theme was mentioned only by staff and relatives. The first example, from staff group two, mentions the related themes of social acceptance and non-

discrimination also; the second example, from staff group one, links equal opportunities with the issues of money and work:

Quote 15:

S12 *I was thinking on the same lines as S9, looking at the opportunity to form relationships...social acceptance...access to equal opportunities...and non-discrimination in the communities...'*

Quote 16:

S5 *I suppose the money thing also raises the inequality that's around...and the desire for a job, the desire for being equal, treated as normal...in terms of quality of life being affected...there are lots of inequalities...*

Structure to Life

Four groups, including both client groups, mentioned this theme. Examples from the staff and relatives groups included the following:

Quote 17:

S2 *I don't know if it's too specific, but predictability in their lives...*
S6 *Consistency of staffing and environment...routine...*
S1 *...we have to be aware that there are some kinds of people who can't cope with lots of choice...*

Quote 18:

R5 *I put down certitude about happenings...*

Clients spoke about the need for *'rules'* and *'routine'*. They noted a desire to *'know where you stand'* and for structures to be congruent with their adult status or *'age appropriate'*.

Non-Judgemental Support

This theme was mentioned in the staff, relatives and trainee psychologists groups. A staff member mentioned the importance to quality of life of *'non-judgmental support'*; a relative noted the need for '*understanding of their problems'*; and a trainee psychologist linked this with respect and *'non-judgmental contact'*.

Expectation of Responsibility

This theme was mentioned by the staff and trainee psychologists groups. A member of staff expressed the theme thus:

Quote 19:

S2 *'I have [put] an expectation on the part of others that they <u>can</u> behave responsibly'.*
MOD *Could you put that another way?*

S2 *People don't automatically assume that they lack responsibility for their actions...people have expectations of a certain level of behaviour to go on, whatever.*
MOD *Something about the way people see them?*
S2 *Yes*

In contrast a trainee psychologist couched the theme in terms of the negative effect of having *'their lives and behaviour scrutinised...all the time'.*

Discrimination

Only staff and clients mentioned non-discrimination. One example from staff was quoted in relation to equal opportunities (see *Quote 15* above).

A further example, in the context of the individual tasks, was as follows:

Quote 20:

S12 *I had down non-discrimination by local community...there is a huge amount of discrimination that goes on out there...(Agreement)...abuse of position by all sorts of people...shopkeepers, local business traders...all sorts of people who abuse their position and take advantage of people with learning disabilities.*

One group of clients mentioned the impact of discrimination on their lives also, within the general group discussion, noting the importance of *'being treated like anybody else'.*

Labelling and Name-Calling

These two related themes were mentioned by staff and clients as part of the general discussion, but were not noted by the other groups. Staff recalled the regimes of institutions in former days:

Quote 21:

S12 *I think that is a good example of how we have moved on...when we looked after lots of people, all the epileptics went in one ward (as they were known) ...and all the behaviour problems went into another ward...all the multiple disabilities went into another ward...and people were classified according to their disability*

The clients identified these two themes as having a key impact on their quality of life, because through labelling they were identified as different, and as a result of name-calling (sometimes linked to labelling e.g. 'mental', 'loony') they were devalued.

Ridicule (being laughed at)

This related theme was mentioned by one of the staff groups as part of the group discussion, but was not noted by other groups.

The theme was prompted by a more general discussion of how adults with intellectual disabilities were viewed by others, both now and in the past:

Quote 22:

S10 *I think it is very difficult to know...whether it is actually acceptance or not...*
S12 *The absolute extremes of behaviour are people pointing and laughing...*

Victimisation

This theme was identified by one of the staff groups as part of the discussion. In this case, victimisation was linked to resettlement in community settings:

Quote 23:

S12 *...a lot of people, of the more able type, who were discharged from hospitals in the early eighties, who were discharged to a lot of housing schemes, council housing schemes round (locality) ...a lot of these people are victimised and they are easy targets for the people who are living there...*

Inter-alia, the seventeen additional themes seemed to relate to aspects of social devaluation and discrimination. The impact of many of these themes may be overlooked by majority groups in populations and cultures, but may be particularly pertinent to the quality of life of various minority or disadvantaged groups (of which adults with intellectual disabilities is but one example).

Summary of Quality of Life Themes

The set of quality of life themes generated spontaneously by the focus group participants covered over 80% of the facets included in the WHOQOL-BREF. In subsequent guided discussion, all the existing WHOQOL-BREF facets were endorsed as relevant for adults with intellectual disabilities.

Multiple individuals and groups identified many of the quality of life themes. As anticipated, each main participant type brought both a common perspective (based on shared experience) and a unique individual viewpoint to the focus group discussions; and the structure provided by the format encouraged both consensus and diversity in the quality of life themes generated.

The five main focus groups (comprising staff, relatives and clients) all engaged in the individual tasks and the related focus group discussions. A triangulation between these three participant types[4], showing the extent of theme agreement, is presented in Table 5.17.

[4] The trainee psychologists (the fourth participant type) did not generate any theme that was not identified by one or other of the main groups.

Table 5.17: Proportion of Theme Agreement by Main Participant Types Staff, Relatives and Clients (N = 31)

Participant Types	Quality of Life Themes Identified (*N* = 59)	
	N	%
3	21	35.6
2	25	42.4
1	13	22.0

As shown in Table 5.17, there was a convergence of two or more of the main participant types in relation to 78% of the quality of life themes. Of the themes identified by only one participant type, 62% were generated by staff, 23% were mentioned by clients and 15% were noted by relatives.

Of the 59 themes generated by the focus groups, 17 (29%) were unconnected to the WHOQOL-BREF facets and seemed to represent aspects of quality of life not measured by the existing instrument. Of these 17 themes, four (24%) were identified by all three main participant types; seven (41%) were noted by two or more participant types; and the remaining six (35%) were mentioned by one participant type only. Therefore, there was a convergence of two or more of the main participant types in relation to 65% of the additional quality of life themes also.

These additional dimensions identified as important to the quality of life of adults with intellectual disabilities were unforeseen initially, but emerged from the pilot work with clear face validity for the client group, reflecting issues of social disadvantage and social justice which characterise many such individuals' interactions with mainstream society. It was hypothesised that these themes represented additional facets relevant to the assessment of the quality of life of adults with intellectual disabilities, which should be incorporated into the adapted instrument as an additional module (as envisaged by the WHOQOL Group) and subsequently tested in the context of the evaluation of the psychometric properties of the pilot instrument.

5.4 Adaptation of the WHOQOL-BREF & Design of the WHOQOL-ID

The information derived from the focus groups provided the framework for the adaptation of the WHOQOL-BREF for adults with intellectual disabilities and the design of the new 'WHOQOL-ID'.

Focus group participants' views on the suitability of the WHOQOL-BREF for the client group formed a starting point for the review of the measure. A number of clear messages emerged from the introduction to the instrument provided during exploration of *key question three* in the focus group procedure.

Participants commented specifically that:

- The language of many items was too complex.

  I don't think many people could cope with that...they would not understand it.

  ...I have [speaking] to people, just to get their feelings about their lives really, and I've found it really quite difficult...but the kinds of questions I have been asking have been simple things like 'are you happy?' 'what do you like?'...very simple kinds of questions.

- Some concepts might be difficult for clients to grasp.

  ...the concept of that is too difficult for them

  ...that's... pretty abstract

- The anchor and intermediate point descriptors of the response scales might be difficult for clients to understand.

  I don't think anyone with learning difficulties is going to be able to respond to that one.

  ...I think you need to show it pictorially ideally... 'smiley faces' is one way

In summary, participants suggested that items should be simple, short, concrete and (if necessary) illustrated by examples; and that the response scales should be supported by pictorial or diagrammatic representations.

There were six main components to the design of the new instrument:

1 Items representing the existing 26 facets of the WHOQOL-BREF were reviewed and revised (as necessary) to enhance suitability and intelligibility for clients with intellectual disabilities.

2 The additional quality of life themes established by the focus groups were reviewed, categorised and incorporated into a set of new ID facets.

3 New items were drafted to represent these new facets, reflecting the original focus group themes.

4 The item response format was reviewed, revised and augmented to maximise the likelihood of clients' direct participation in use of the new measure.

5 The set of introductory socio-demographic questions were reviewed and revised for the client group.

6 The instructions for administering and completing the scale were reviewed and revised consistent with the requirements of the new measure and suitability for the target population.

Item revision

The wording of the 26 WHOQOL-BREF items was reviewed. Following the suggestions of focus group participants, a number of alternative expressions of each item were drafted, ensuring that congruence with the relevant facet definition was maintained and, as far as possible, preserving semantic equivalence to the original item. The refining of item wording then took place in two consultation stages.

Firstly, advice was sought from a small group of practitioners with specific expertise in intellectual disabilities, including experience of interviewing clients in relation to assessment, treatment and care in both hospital and community settings. For each facet, the original WHOQOL-BREF item, the comparator WHOQOL-100 item, and the re-worded alternative item versions were presented. This group (panel one) were asked to consider the suitability of the original wording of each item and the alternatives, and invited to suggest amendments or replacements. The importance of semantic equivalence and avoidance of ambiguity was stressed, as was the requirement to avoid phraseology that might convey moral overtones (e.g. 'good' or 'bad').

This first consultation on the possible re-wording of items produced a number of suggestions that were consistent with the comments of focus group participants. For example, it was suggested that the BREF item phrase *'to what extent...'* should be replaced by the simpler *'how much...'* and the BREF item phrase *'how satisfied are you...'* should be replaced with *'how happy are you...'*. Other suggestions included the use of concrete examples for abstract, or conceptually complex, items (e.g. *'going to church'* in relation to item 6, spirituality) and 'hints' that could be used to prompt responses. Finally, some specific replacement vernacular (in common usage by ID clients) was suggested to assist understanding (e.g. substitution of *'tablets'* for *'medicines'* or *'medical treatment'* in relation to item 4, medication).

Taking account of the suggestions made by panel one, the principal researcher and a graduate research assistant reviewed the item pool and a consensus approach was taken to the selection of a 'preferred set' of re-worded items, together with associated prompts for 11 of the 26 items.

Secondly, advice was sought from a small group of practitioners with specific expertise in communication problems and related therapeutic approaches in relation to adults with intellectual disabilities. This group (panel two) were presented with the original BREF item and the preferred draft of the re-worded item for each facet. They were invited to comment on the conceptual match and the suitability of the wording, and invited to suggest amendments.

In addition, soundings were taken from this group about the potential of a set of four supplementary open-ended questions about quality of life, designed to capture a 'snapshot' of the current position in life and future aspiration of respondents. It was envisaged that these questions might add richness to the WHOQOL-ID measure by revealing aspects of life experience and quality of life from the clients' perspective and, for clients able to respond directly, in their own words. These supplementary questions were:

- What is the best thing about your life right now?
- What is the worst thing about your life right now?
- Is there anything you would like to change about your life?
- What would you like for the future?

Two specific, and linked, recommendations emerged from this second stage of consultation in relation to enhancing the understanding of items by adults with intellectual disabilities, and improving the reliability of subsequent responses. The first recommendation was to use a 'two-step' approach to the format of some items, thus providing the opportunity for respondents to relate to the question in terms of the overall scale descriptors first, and then to consider the issue of 'extent'. For example, the original BREF item '*How satisfied are you with your health?*' could be revised for ID clients, with simplified wording, as *'How happy are you with your health?'*. However, by asking this in a different format *'Are you happy or unhappy with your health?'* respondents could approach the question in two stages, by considering which end of the response continuum described their view of their health in general terms first (e.g. they might be *happy* with their health) and then considering how happy they were with their health (e.g. *quite happy* or *very happy*). The second recommendation was to incorporate symbols or other pictorial representations to illustrate or augment response scales (see below).

With these caveats, panel two endorsed the general approach to item re-wording, the use of prompts, and the supplementary open-ended questions. The original BREF items together with the final revisions of these for the WHOQOL-ID are presented in Table A5.25 in Appendix 5.

New facets

The additional quality of life themes established by the focus groups were reviewed to determine the most suitable classification into new facets to form the additional module in the WHOQOL-ID.

The 17 themes seemed to be related within an overall domain representing expressions of *social justice* of which five main dimensions were identified. Some themes seemed to reflect the impact of *social devaluation* (e.g. being laughed at, being called names); some themes seemed to reflect aspects of *discrimination* (e.g. non-discrimination, victimisation); some themes seemed to relate to opportunities and resources for achieving *social equity* (e.g. advocacy, equal opportunities); some themes seemed to relate to *empowerment and self-*

determination (e.g. control of life, choice); and others themes appeared to reflect *social acceptance* (e.g. acceptance, respect).

However, as shown in Table 5.18, depending on the level of facet definition adopted, each dimension could be further subdivided, to form a set of ten facets.

Table 5.18: New WHOQOL-ID Dimensions and Facets

	Dimensions	Facets
1	Social devaluation	Ridicule & Stigmatisation
2	Discrimination	Discrimination & Victimisation
3	Social equity	Enabling & Advocacy
4	Empowerment & self determination	Empowerment & Autonomy
5	Social acceptance	Acceptance & Respect

Appropriate facet classification was discussed with panel one, in the context of generating possible new items, and with panel two, in the context of consultation on the new item pool. As views were divided about the most suitable level of taxonomy, and no clear consensus emerged, a decision was taken to avoid an a priori reductionist approach, maintaining facet identity for subsequent evaluation in relation to the psychometric properties of the new scale.

Ultimately, all ten facets (two facets per dimension) were reflected in the range of items taken forward into the pilot WHOQOL-ID. The relationship between these dimensions, facets and the additional quality of life themes generated by the focus groups, along with the basic facet definitions[5], is presented in full in Table A5.26 in Appendix 5.

New items

The generation, and subsequent refinement, of new items was subject to a similar consultation process as that described for the revised items, and followed the core procedural elements employed in the development of the WHOQOL-100 (WHOQOL Group, 1994b, 1995).

Firstly, panel one were invited to review the appropriateness of the draft facets and contribute to the formulation and discussion of new items to represent the additional focus groups themes. Following the original WHOQOL methodology, it was emphasised that new items should be phrased as questions, not statements; using simple language and avoiding ambiguity; in a style similar to the original items i.e. conforming to the 'WHOQOL typology'; in a format amenable to a rating scale; covering the key aspects of the theme/facet in a way that was

[5] Sources: The Oxford English Reference Dictionary (1996), The Chambers Dictionary (1998), and Encarta World English Dictionary (1999)

applicable to people with a range of intellectual disabilities (from profound to borderline) and which illustrated clearly aspects of a person's quality of life. For each new item generated, the group were asked to consider the extent to which it reflected the facet conceptually, its relevance to the target population and the suitability of wording for the client group.

This consultation produced only a small pool of suggested items (1-2 per facet). Therefore, taking account of the initial work undertaken by panel one, the principal researcher and a graduate research assistant expanded (rather than reduced) the item pool, prior to further consultation.

Secondly, panel two were asked to review the expanded item pool (3-4 items per facet), comment on the suitability of item wording and the item-facet conceptual match, and invited to suggest amendments (consistent with semantic equivalence) or replacements (consistent with facet definitions).

The second stage of consultation produced general endorsement of the approach to new items; and following discussion a number of amendments and additions were made to the item pool. However, a number of items in this further expanded item pool (4-5 items per facet) were very similar, and amounted to slight wording variations of substantially the same item. Therefore, the principal researcher and a graduate research assistant reviewed the items and a consensus approach was taken to identifying those items with the greatest degree of semantic equivalence, reducing the item pool slightly for the third stage of consultation.

Finally, the residual pool of new items was discussed independently with two experienced researchers[6] and a consensus approach was taken to selection of the final new item set. For each of eight facets, one item was selected, consistent with the WHOQOL-BREF facet-item ratio. However, for each of two facets (advocacy and autonomy) two items were selected. For advocacy, the focus groups noted the relevance of advocacy on behalf of clients (e.g. citizen advocacy, staff advocacy), and also self-advocacy (e.g. as part of a rights group or a clients council). Similarly, for autonomy, the focus groups identified the importance of so-called 'big choices' (e.g. where to live) and also routine day-to-day aspects of autonomy. Therefore, for these facets, items were selected to represent both facet aspects for further evaluation as part of the analysis if psychometric properties. The full set of new items is presented by facet in Table A5.27, and as part of the fully revised WHOQOL-ID at A5.36, in Appendix 5.

Response scales

The response scales (including descriptors of anchor points and intermediate scale points) associated with all potential WHOQOL-ID items were reviewed,

[6] Both supervisors, one with specialist experience of WHOQOL development and the other with specialist experience in intellectual disabilities

revised and augmented to assist understanding and maximise the likelihood of clients' direct participation in completing the measure.

The twenty-six items in the WHOQOL-BREF were linked to six different five-point Likert type response scales, derived from those used in the WHOQOL-100. These response scales are shown in Table 5.19

Table 5.19: Response Scales for WHOQOL-BREF

Items	Anchor 1	2	Intermediate Scale Points 3	4	Anchor 5
1, 15	Very poor	Poor	Neither good nor poor	Good	Very good
2, 16-25	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
3 - 6	Not at all	A little	A moderate amount	Very much	An extreme amount
7-9	Not at all	A little	A moderate amount	Very much	Extremely
10-14	Not at all	A little	Moderately	Mostly	Completely
26	Never	Seldom	Quite often	Very often	Always

In adapting the response scales for the WHOQOL-ID, consideration was given to the appropriateness of a five-point scale for those ID clients with the capacity to complete the scale directly. The relevant literature was reviewed for evidence to support the direct use of five-point scales with the target population, compared with shorter scales or simpler response choices. Examples were found of quality of life and life satisfaction instruments using dichotomous scales (e.g. *Life Experience Checklist*, Ager 1998); three-point Likert scales (e.g. *Quality of Life Questionnaire*, Schalock and Keith, 1993); and five-point scales (e.g. *ComQol*, Cummins, 1993). However, in a review of such scales for people with intellectual disabilities Cummins (1997) suggested that experience with the *ComQol* scale had indicated that people with mild intellectual disabilities can use a five-point scales reliably, and pointed out the superiority of these in relation to the proportion of the underlying variation reflected (approximately 95% for five point scales compared with only 67% for three-point scales). This seemed to suggest that anything less than a five-point scale would be sub-optimal for those with mild intellectual disabilities; and although some people with moderate intellectual disabilities might be able to participate in direct scale completion more reliably if a less complex response scale was employed, for those with higher levels of impairment (e.g. severe and profound intellectual disabilities) it was anticipated that staff support and/or proxy assessments would be required.

On balance, despite slight concerns about the degree of difficulty involved in responding to five options, there was a strong rationale to maintain the five-point scale in order to facilitate comparison with the original WHOQOL instruments. Furthermore, it was anticipated that the incorporation of the potential two-step

format for many items (described above) provided a simplified approach, which might support performance on the five-point scales for a greater proportion of clients.

Ultimately, the decision was taken to maintain the five-point scales in the pilot instrument, for subsequent trials with the client group as part of pilot study two. Similarity of anchor points and intermediate scale point descriptors were maintained as far as possible also, but four main revisions were made following suggestions from focus group participants and the consultative panels.

Firstly, some wording was simplified (but semantic equivalence maintained) to make the response scales more intelligible for the target population. For example, the *very dissatisfied-very satisfied* scale was re-worded *very unhappy-very happy*; and the *not at all-an extreme amount* scale was simplified to *not at all-a great deal*, with an associated prompt *an extremely big amount.*

Secondly, alternative scales linked to revised item wording replaced some response scales. For example, the revised wording of item 13, information (*BREF: How available to you is the information that you need in your day-to-day life? ID: Is it easy or difficult to get the kind of information you need in your day-to-day life?*) provided the basis for a new response scale *very difficult-very easy.*

Thirdly, in the BREF, the modifying adjective 'very' was used in connection with both of the upper scale points (at scale point 5 for two response scales and at scale point 4 for a further three response scales). It was anticipated that this might be confusing for ID clients, and a consistent approach to all response scales was sought by employing 'very' as a modifier for upper scale point 5 only, and introducing 'quite' as a modifier for the intermediate scale point 4.

Fourthly, the concept of 'neither one, nor another' (e.g. 'neither satisfied nor dissatisfied') was expressed more simply as '*about in the middle'* to increase intelligibility for adults with intellectual disabilities.

Table 5.20: Revised Response Scales for WHOQOL-ID

Items	Anchor 1	2	Intermediate Scale Points 3	4	Anchor 5
1-2, 10-12, 16-25	Very unhappy	A bit unhappy	About in the middle	Quite happy	Very happy
3 - 6	Not at all	A little bit	A medium amount	Quite a lot	A great deal (an extremely big amount)
7, 13-15	Very difficult	A bit difficult	About in the middle	Quite easy	Very easy
8	Very unsafe	A bit unsafe	About in the middle	Quite safe	Very safe
9	Very unhealthy	A bit unhealthy	About in the middle	Quite healthy	Very healthy
26-38	Never	Not very often	Sometimes	Quite often	Always

The final set of response scales for the WHOQOL-ID is presented in full in Table 5.20.

Finally, following the recommendations of both focus group participants and panel two, the responses scale point descriptors were augmented by pictorial representation through the use of 'smiley' faces. These were simple black and white line drawings of faces illustrating very smiling (mouth turned up), through to very unsmiling (mouth turned down) expressions. Two sets of smiley faces were employed to match the positive and negative orientation of items, as shown in Figures 5.1 and 5.2.

Figure 5.1: Smiley Faces: Negative – Positive Response Format

Figure 5.2: Smiley Faces: Positive – Negative Response Format

The full size versions of the six WHOQOL-ID response scales, showing the five point scale, the anchor and intermediate scale point descriptors, and the smiley faces are presented in full at A5.28-A5.35 in Appendix 5.

Socio-demographic questions

The socio-demographic questions included in the section 'ABOUT YOU' at the start of the WHOQOL-BREF were reviewed, and minor revisions made to enhance suitability for adults with intellectual disabilities.

Firstly, the response choices available for the item on education were expanded to include a fifth category 'Special School' to reflect a common educational background for many people with intellectual disabilities. The highest level of education (Tertiary) remained in the new scale to capture the educational experience of those ID clients who had attended courses in Colleges of Further Education.

Secondly, the wording of the item on health (*BREF: Are you currently ill?*) was revised (*ID: Are you currently ill, or in poor health?*) to capture some of the chronic health problems associated with people with intellectual disabilities, as well as more acute illnesses.

Thirdly, an additional three-part item on disability was added (using a parallel format to the BREF health question) in an attempt to capture ID clients' perceptions of the presence of disability, it's nature, and its impact (if any) on their day-to-day life.

Instructions

The instructions for completing the scale were reviewed and minor revisions made consistent with the requirements of the new measure and its suitability for the target population.

Firstly, the language was simplified (as far as possible) to make the instructions more accessible and 'user-friendly' for people with intellectual disabilities.

Secondly, the presence of the 'prompts' introduced to support some items was signalled; their purpose was described; and an illustration of a prompt included in the preparatory non-scoring item example.

Thirdly, the 'smiley faces' introduced to augment the response scales were signalled and illustrated.

Fourthly, a sentence was added (*There are no right or wrong answers – just answer what is true for you*) to emphasise the subjective nature of the assessment, and the difference between this and many other 'tests' that individuals with intellectual disabilities may have been asked to complete on other occasions.

Finally, considering the potential for literacy problems in the target population, specific mention was made in the instructions of the acceptability of seeking assistance to fill in the assessment form. A related subsidiary question was added to the general item at the end of the scale (*BREF: Did someone help you fill out this form?*) to capture information about any such helper (*ID: If, yes, who was that person?*)

Summary

Information gathered as part of the focus group discussions was used as the initial starting point to revise and adapt the WHOQOL-BREF to maximise relevance and suitability for adults with intellectual disabilities.

The approach adopted for the first phase of development of the WHOQOL-ID incorporated the basic strengths of the methodological steps underpinning the development of the original WHOQOL-100 measure. These key features of instrument design were followed (as far as possible) in determining facets; revising, drafting and selecting items; and generating response scales. Similar procedures were used in relation to panel consultation and review also.

However, within the scope of the present study, the scale of the consultation and review was much more limited; and although the issue of reliability was acknowledged in the consensus approach which guided decision-making, there were times when consensus was difficult to achieve (e.g. in respect of level of facet definition). In a larger funded study, a more extensive and controlled use of expanded 'expert panels', allowing a more robust approach to reliability (e.g. using blind ratings and reporting formal measures of inter-rater reliability) would be recommended to improve the process of scale development.

Following the development work and the revisions described, the new measure was piloted under the acronym WHOQOL-ID. The trial version of the adapted measure is presented at A5.36 in Appendix 5.

Chapter 6

Pilot Study 2: Development of the WHOQOL-ID

A trial of the pilot instrument was conducted in relation to a small group of adults with intellectual disabilities in both hospital and community settings. The individuals selected for this pilot study resided in a range of accommodation similar to, but separate from, that identified for the subsequent main study, in order to avoid effects due to short timescale repeated measures on the same participants that might affect the main study adversely e.g. practice effects if the instrument remained unchanged, or cross study contamination if the measure was revised.

The objectives of the second pilot study were to:

1 Carry out a field trial of the new WHOQOL-ID with a group of ID clients drawn from, and broadly representative of, the target population; and carry out an initial analysis of the psychometric properties of the measure

2 Collect and analyse feedback from respondents (both adults with intellectual disabilities and proxy staff) on their experience of completing the assessment and their suggestions (if any) for scale improvement

3 Identify the requirements for revision, or refinement, of the pilot scale; and produce a final version of the instrument for the main study.

6.1 Design and Methodology of Field Trial

The participants of the field trial of the pilot instrument were adults with intellectual disabilities contemporaneously in receipt of either residential healthcare (funded by the NHS) or residential social care (funded by the local authority). The facilities selected were broadly representative of services available for both short-term assessment and treatment, and medium to long-term care and support, for adults with intellectual disabilities. Thus, the pilot study participants were drawn from similar sections of the ID population to those identified in the index and comparator group in the main study, and were broadly representative of the target group for the WHOQOL-ID.

The methodology employed in the pilot study was similar to that of the main study, and involved the same essential ethical safeguards with regard to voluntary participation, informed consent and confidentiality.

Participant Types and Service Models

The healthcare group were residents of two different healthcare facilities. The first of these (HC1) was a small NHS community facility based in a large semi-detached house (regular housing stock, adapted for the purpose) located in an ordinary residential street close to the campus of the parent hospital. This house was owned and managed by the NHS, and staffed by a conventional clinical team of nursing and medical personnel, supported by other visiting professionals. The second facility (HC2) was a modern, slightly larger, and more traditional residential unit located directly on the hospital campus. A conventional clinical team staffed this unit also, supported by clinical psychologists and a range of therapists (e.g. speech therapy, art therapy).

The social care group resided in supported accommodation operated by two different voluntary sector providers. All four social care homes (SC1-4) were based in ordinary houses (regular housing stock) of varying size in local community neighbourhoods located across the region; and were staffed on a 24 hour basis by a mixture of qualified staff (mainly from residential care or nursing backgrounds) and unqualified support workers. Residents of these houses received local general practitioner and other primary care services as required, and could access additional support from peripatetic community learning disability teams by referral.

A total of thirty-four adults with intellectual disabilities took part in the pilot study. Approximately equal numbers were in healthcare facilities (47%) and in receipt of social care (53%). The distribution of participants by care type and project is presented in Table 6.1.

Table 6.1: Participants by Care Type and Project

Care Type			Residential Project			
	N	%	Code	Places	*N*	%
Healthcare	16	47.1	HC1	6	5	31.2
			HC2a	6	5	31.2
			HC2b	6	6	37.5
Social care	18	52.9	SC1	5	4	22.2
			SC2	4	3	16.7
			SC3	6	6	33.3
			SC4	5	5	27.8
Total Group	34					

As shown, the campus based healthcare unit was the largest facility (12 places), but within this, residents were managed in two physically linked but separate sub-units of six places. All the projects based in community houses were fairly small (range 4-6 places) and were 'domestic' in both scale and décor. All the

settings offered single bedrooms, affording a degree of privacy and individual space for clients; and all had public rooms of sufficient size and number for the residential group to live in a 'family' type of arrangement (e.g. for shared meals and leisure activities).

Characteristics of Participants

The demographic data collected on participants were those featured in the introductory section of the pilot WHOQOL-ID. As the number of participants involved in the pilot study was small, the demographic data are reported mainly at the level of the total pilot group and the care type subgroups.

Gender

Overall, approximately three quarters of the pilot group were male and one quarter was female. As shown in Table 6.2, the social care subgroup was fairly evenly balanced in terms of gender (56% male and 44% female); but the healthcare subgroup was predominantly male (94%) and reflected the over-representation of men in both NHS facilities and in the intellectual disabilities population (Emerson et al 2001).

Table 6.2: Participants by Gender

Gender	Healthcare (*N* = 16)		Social Care (*N* = 18)		Total Group (*N* = 34)	
	N	%	*N*	%	*N*	%
Male	15	93.7	10	55.6	25	73.5
Female	1	6.3	8	44.4	9	26.5

Age

In the total pilot group, half the participants were aged below 40 years and half were 40 or above. However, as shown in Table 6.3, the healthcare group were younger than the social care group overall, with 80% of those in healthcare aged under 40, but 80% of those in social care aged 40 or over.

Table 6.3: Participants < and ≥ 40 years

Age	Healthcare (*N* = 16)		Social Care (*N* = 18)		Total Group (*N* = 34)	
	N	%	*N*	%	*N*	%
< 40	13	81.2	4	22.2	17	50.0
≥ 40	3	18.8	14	77.8	17	50.0

The mean age of the total pilot group was 38.3 years (*SD* 9.4). As shown in Table 6.4, the mean age of the healthcare group was 32.3 (range 19-43) and the mean age of the social care group was 43.7 (range 31-58).

Table 6.4: Participants by Age

Group	*N*	Age Range	Mean Age	*SD*
Healthcare	16	19 - 43	32.3	± 7.27
Social Care	18	31 - 58	43.7	± 7.72
Total Group	34	19 - 58	38.3	± 9.41

Education

An attempt was made to collect basic data on the highest level of education received by participants. However, this proved difficult. Some ID clients who responded directly did not know, or could not remember, what type of school they attended; and some staff proxy respondents did not know much of the educational background of their clients. Overall, there was a lack of clarity about the education of approximately 35% of participants. It appeared most likely that the remaining 65% of participants had attended special school; however, these data may be unreliable. It was noteworthy that staff reported little evidence of the educational background of clients in the formal health or social care records, and it may be that reliable data could only be obtained by approaching the education authority for access to school records. However, this was beyond the scope of the pilot study.

Marital Status

Data were collected on the marital status of participants and in this pilot group all were reported to be single. This would be an unusual finding in a sample of the general population of a similar age range, but was not unexpected within an ID sample, reflecting the lack of opportunity for many adults with intellectual disabilities to establish and sustain relationships within 'cared-for' settings.

Health

The majority of pilot study participants were reported to be in good health, with a very similar balance of health status reported across care settings. As shown in Table 6.5, approximately 80% of participants in the total pilot group, and in both healthcare and social care subgroups, were not ill, nor in poor health, compared with only 20% who were ill or in poor health. A health problem was reported for three clients in the healthcare subgroup, all of which were physical (one person had a broken leg, and two people reported weight related problems). In the social care group three people had physical health problems (one person had arthritis,

another had diabetes and epilepsy, a third described 'appendix related' problems) and one person had a mental health problem.

Table 6.5: Participants by Health Status

Ill or Poor Health	Healthcare (*N* = 16)		Social Care (*N* = 18)		Total Group (*N* = 34)	
	N	%	*N*	%	*N*	%
Yes	3	18.7	4	22.2	7	20.6
No	13	81.3	14	77.8	27	79.4

Disability

As shown in Table 6.6, approximately 60% of the total pilot group were reported as having a disability, the remaining 40% being evenly split between those reported as not having a disability and those responding 'don't know'. This was a surprising finding, given that all participants had intellectual disabilities.

Table 6.6: Participants by Disability

Disability	Healthcare (*N* = 16)		Social Care (*N* = 18)		Total Group (*N* = 34)	
	N	%	*N*	%	*N*	%
Yes	11	68.7	9	50.0	20	58.8
No	1	6.3	6	33.3	7	20.6
Don't Know	4	25.0	3	16.7	7	20.6

Since the pilot item was worded to capture a subjective perspective of the presence or absence disability (*Do you think you have a disability?*) it was possible that there was a difference in response pattern between clients responding directly and staff responding on behalf of clients. However, as shown in Table 6.7, analysis of disability by response mode suggested a broadly similar pattern of responding overall, with an average of 58% of participants reporting the presence of a disability and 42% reporting either the absence of disability or responding 'don't know'.

Table 6.7: Participants' Disability by Response Mode

Disability	Direct (*N* = 13)		Proxy (*N* = 21)	
	N	%	*N*	%
Yes	7	53.8	13	61.9
No	2	15.4	5	23.8
Don't Know	4	30.8	3	14.3

In contrast, further analysis by care type and response mode revealed a different picture. As shown in Table 6.8, in the healthcare subgroup, 100% of the proxy respondents reported the presence of a disability; but of the clients responding directly, approximately 30% reported the presence of disability and 70% reported either no disability or responded 'don't know'. However, in the social care group, the pattern was reversed. Approximately 30% of proxy respondents reported the presence of disability and 70% reported no disability, or responded 'don't know'; but of the clients responding directly, 83% reported the presence of a disability and 17% reported no disability.

Table 6.8: Participants' Disability by Care Type and Response Mode

Disability	Healthcare (*N* = 16)				Social Care (*N* = 18)			
	Direct (*N* = 7)		Proxy (*N* = 9)		Direct (*N* = 6)		Proxy (*N* = 12)	
	N	%	*N*	%	*N*	%	*N*	%
Yes	2	28.6	9	100	5	83.3	4	33.3
No	1	14.3	-	-	1	16.7	5	41.7
Don't Know	4	57.1	-	-	-	-	3	25.0

This suggested that healthcare staff had a clearer perception of, or were more willing to report, disability in their clients than social care staff; but that social care clients were more aware of, or more willing to report, their disability than healthcare clients. This finding requires to be treated with much caution, as the numbers in the subgroups were very small at this level of analysis. However, the different response patterns of proxy respondents may reflect aspects of the service models in which they work. The assessment and treatment model of healthcare is directed explicitly towards identifying problems and needs, and may overemphasise these sometimes, to the detriment of other strengths. In contrast, the model of social care based on the principles of 'normalisation' (Nirje, 1976; Wolfensberger, 1972, 1983) may underplay differences (including disabilities) in an attempt to support strengths and foster social participation.

Similarly, the different response pattern of clients themselves may reflect the environments in which they receive care and support. Social care clients may be brought face-to-face with their disabilities in relation to their presence in local neighbourhoods of predominantly non-disabled people. On the other hand, for healthcare clients living on, or in close proximity to, a hospital campus, the majority of their peers and social contacts may be other disabled individuals, and against this background, clients may perceive their own disabilities as minor or non-existent. In addition, some healthcare clients in treatment settings may have concurrent mental health problems (e.g. affective disorders) that may impact on self-perception, such that they are more prone to unrealistic assessments of their situation.

Recruitment and Consent

Prior to the pilot study, negotiations about access to local intellectual disability services, and potential participants, had been concluded successfully with the NHS, local authorities, and voluntary sector service providers, in relation to the main study (see Chapter 8). The support gained for the project during these introductory discussions formed the basis for an additional approach to one NHS and two voluntary sector providers, in order to recruit clients not included in the cohort for the main study to take part in the initial trial of the WHOQOL-ID.

Participants were recruited to the pilot study by a combination of methods including telephone calls, letters, initial meetings with senior care staff and small introductory meetings with clients and/or proxy staff.

All potential participants were provided with standardised information about the research (including information on confidentiality, participant anonymity and the possibility of refusal) and given *at least* 24 hours, but usually much longer, to consider whether or not they wished to take part. All those who ultimately agreed to participate were requested to sign an appropriate consent form.

Healthcare clients

Healthcare clients were approached initially via the medical and nursing staff responsible for their care. Meetings were held with the appropriate consultant psychiatrist and charge nurse during which the purpose of both the main study and the pilot work was explained; the basic methodology of the pilot study was described; the participant information and consent procedures were outlined; and agreement to approach their patients as potential pilot study participants was requested. In addition, preliminary guidance was sought about the capacity of each potential subject to participate directly in the study, in relation to both the consent and assessment procedures. For the purpose of the study it was agreed that if the capacity of an individual client were unclear, it would be assumed that the person could participate directly, unless subsequently this was shown not to be practicable. This avoided the possibility of staff ruling out any client erroneously, and ensured that the number of clients contributing directly to the quality of life assessment, at least to some extent, was maximised.

Small group meetings were held with those clients considered to have the capacity to understand the pilot study purpose and procedure, to make an informed decision about taking part, and to participate directly. Clients identified as potentially more comfortable with a known member of staff present during the assessment, or requiring some staff support to respond meaningfully (e.g. to aid communication) were included in these meetings also. A full description of the project was given and clients were encouraged to ask questions or raise concerns. The participant information sheet (A6.2 in Appendix 6) and client consent form (A6.4 in Appendix 6) were explained in detail and, where necessary, the documents were read out and explained section at a time, in language tailored to

the match the clients' level of understanding. It was stressed that each individual could make up their own mind about whether to take part in the pilot study or not, and that no unfavourable consequences would ensue from a decision not to participate. The clients were informed that the charge nurse had copies of these documents, so that if they had questions or concerns after the meeting, they could approach this member of staff for further discussion or clarification. Subsequently, the charge nurse was contacted by telephone to establish if any of the clients had proceeded to give formal consent for participation in the pilot study.

For each client considered to lack the capacity to understand the pilot study purpose and procedure, to give consent and thus to participate directly, an appropriate proxy member of staff (e.g. the client's key worker, or the person considered to know the client best) was identified by the charge nurse. Similar small group or individual meetings (as dictated by workload and staff rosters) were held with these proxy staff, providing exactly the same information as received by the client group (as outlined above). The content and purpose of the staff participant information sheet (A6.3 in Appendix 6) and the staff consent form (A6.5 in Appendix 6) were explained and discussed, and the proxy staff were invited to participate in the pilot study on behalf of their clients. Subsequently, follow-up contact was made with these staff to establish their decision about participation in the pilot study.

A total of 18 healthcare clients were approached to participate in the study. Of these, nine clients were approached directly, and nine were approached indirectly via proxy staff. Of the nine 'direct' clients, seven attended the initial meeting and consented to take part in the pilot study. Ultimately, all seven clients participated in the study: six clients participated individually; and one client completed the assessment in combination with supporting staff. Two of the initial nine direct clients did not take part in the pilot study: the first client refused at the stage of the introductory meeting; and the second client was withdrawn on medical advice, as a result of concurrent mental health problems.

Proxy staff attended the initial meeting on behalf of the nine 'indirect' clients, all consented to take part in the pilot study, and ultimately all nine completed the assessments on behalf of their clients.

Social care clients

Social care clients were approached initially via the appropriate senior manager of the voluntary organisation providing their care. This senior level contact was made by a combination of letters (see example at A6.1 in Appendix 6) and face-to-face meetings at which the purpose of both the main study and the pilot work was explained; the basic methodology of the pilot study was described; the participant information and consent procedures were outlined; and agreement to approach some of their clients as potential pilot study participants was requested. As a result of this, four social care projects were identified for the pilot study.

Subsequently, a meeting was arranged with the appropriate project manager at which the study was outlined again in detail, and preliminary guidance sought about the capacity of each potential subject to participate directly, in relation to the both the consent and assessment procedures. Finally, small group meetings were held with both clients and designated proxy staff, and identical recruitment and consent procedures as described for the healthcare clients were followed.

A total of 20 social care clients were approached to participate in the study. Of these, 10 clients were approached directly initially, and 10 were approached indirectly via proxy staff. Of the 10 'direct' clients, eight attended the initial meeting and consented to take part in the pilot study. Ultimately, all eight clients participated in the study: five clients participated individually and directly; one client completed the assessment in combination with supporting staff; and proxy staff completed the assessment on behalf of the remaining two clients after direct participation proved impractical. Two of the initial 10 direct clients did not take part in the pilot study as both refused at the stage of the introductory meeting.

Proxy staff attended the initial meeting on behalf of the 10 'indirect' clients, all consented to take part in the pilot study, and ultimately all 10 completed the assessments on behalf of their clients.

Summary of final group of participants

The final group of pilot study participants is summarised by care type and response mode in Table 6.9.

Table 6.9: Participants by Response Mode

Respondent	Healthcare (*N* = 16)		Social Care (*N* = 18)		Total Group (*N* = 34)	
	N	%	*N*	%	*N*	%
Client Direct	6	37.5	5	27.8	11	32.4
Client + Staff Combined	1	6.3	1	5.6	2	5.9
Staff Proxy	9	56.3	12	66.7	21	61.8

Overall, 38% of clients participated in the study directly, either individually or with staff support Proxy staff participated on behalf of the remaining 62% of clients. The balance of direct and indirect participation was broadly similar across the care type subgroups, however a slightly larger proportion of healthcare clients participated directly (44%) compared with social care clients (33%). This was considered to be an adequate balance of respondent types, and response modes, to meet the objective of collecting and analysing feedback from both adults with intellectual disabilities and proxy staff on experience of completing the pilot WHOQOL-ID.

Procedure

The pilot study measure was the final pilot version of the WHOQOL-ID as described in Chapter 5 and presented in full in A5.36 in Appendix 5.

The main procedural elements of the pilot study design were common to both participant and respondent types. All the assessments were administered by face-to-face interview. The interviews were arranged in advance and held at the health and social care projects in suitably comfortable, distraction-free settings (mostly small 'quiet rooms', or project living rooms unused by others at the time). Home-based interview arrangements were made to maximise the likelihood of relaxed participation (Atkinson, 1988); and in further pursuit of participant availability and stress-free co-operation, appointments were set at times to suit each individual client or staff proxy, in order to minimise impact on their routine and avoid disruption to their usual pattern of day activities or work. As a result of this, the pattern of assessment appointments varied across projects: in some projects only one interview was scheduled on a given day; but in other projects a set of interviews, with a range of respondents, was arranged on the same day.

Pre-interview

Before each interview appointment (or set of appointments), a check was made to ensure that the participant(s) had signed and returned the pilot study consent form. In order to maximise their comfort with the task, participants were offered the opportunity to clarify any last minute points about the research purpose, pilot study procedure, or use of the outcome data.

Assessment

At the start of the interview, the WHOQOL-ID was introduced; a general overview of the method of completing the scale was presented; and the introductory socio-demographic section of the measure (About You) was completed.

Subsequently, the Instructions section was reviewed and explained in detail; and participants were invited to work through the non-scoring item example. This example was of particular importance in the case of clients designated by their carers as having the capacity to respond directly, as it provided an opportunity for either confirmation of this capacity, or indication of the need for assistance.

The assessment was commenced and completed in a standardised manner, with respondents being asked to think about their life in the last two weeks. For each section, the introductory directions were read out, the questions were asked in sequence, and the participants' response to each item was noted on the record form.

Finally, the method of assessment completion (direct or indirect), the name of the staff proxy (if applicable) and the time taken for the assessment was noted; and respondents were invited to make comments about the questionnaire.

Feedback form

Following the assessment, each respondent was asked to complete the Pilot Study Feedback Form (A6.6 in Appendix 6) on which information about the experience of completing the WHOQOL-ID was collected. Of particular interest were respondents' views on which questions (if any) were difficult to understand; which questions respondents rated as good (or the 'best') questions; whether any questions were considered to be irrelevant; whether (for clients) the smiley faces were found to be helpful; and whether respondents thought anything was missing from the assessment. As the feedback was related to *respondents*, not subjects, one feedback form was completed for each client who responded directly, and one feedback form was completed for each staff participant, irrespective of the number of proxy assessments they completed.

Expression of thanks

Participants were thanked for taking part in the pilot study, for giving their time and attention to the assessment, and to providing feedback. A few days after each interview, a short letter of thanks was sent to each participant also, an example of which is shown in A6.7 in Appendix 6.

Post interview

For each client who participated in the study, a copy of the signed consent form was returned to the relevant charge nurse (healthcare clients) or project manager (social care clients) as a record of the agreement to take part and the consenting respondent (client or staff proxy).

Procedural Variations

There was one procedural variation only, which related to the presentation of the WHOQOL-ID response scales for the two response modes: clients responding directly and staff responding on behalf of clients.

Proxy staff

To support the interview format, staff respondents were provided with a laminated prompt card on which the full range of response scales (including numerical scale points and descriptors) was reproduced. The prompt card was introduced to reduce the necessity to repeat response scales if respondents required reminders of the options available for a particular item. The appropriate response scale was included in the question format for each item as part of the

interview procedure, but in addition staff respondents were directed to the correct response scale on the prompt card as they considered their answer. The staff participant response scale card is shown A6.8 in Appendix 6.

Clients

For clients responding directly to the assessment, the standard WHOQOL-ID response scales were augmented with the appropriate set of 'smiley faces' (as described in Chapter 5 and presented in full in A5.28 – A5.35 in Appendix 5). In recognition of the prevalence of visual impairment in the intellectual disabilities client group (Kerr et al, 1996), and in order to avoid possible confusion, these response scales were produced in large format and were presented one at a time, as required. As for staff proxy respondents, the appropriate response scale was included in the question format for each item as part of the interview procedure, but additionally, and simultaneously, client respondents were directed to the correct response scale in order to better consider their answer. It was hoped that this methodology would reduce the occurrence of potential 'candidate answers' offered (and possibly changed) within the context of the brief pauses inevitable in the serial listing of response alternatives (Antaki and Rapley, 1996); and reduce the tendency to select the last option presented (Sigelman and Budd, 1986).

Assessment Scoring and Pilot Database

SPSS (Windows) software (Version 10 and subsequently Version 11) was used to collate the data into a pilot study database. The WHOQOL-ID assessments were scored according to the guidance set out for the original WHOQOL-BREF in the Draft WHOQOL User Manual (WHO, 1998). Related SPSS Syntax provided in the Draft WHOQOL User Manual was customised for the WHOQOL-ID pilot version (i.e. allowing for additional items within an extra domain) and the WHOQOL-ID item data were checked, recoded as necessary (reversing negatively phrased items), and domain scores were computed. The socio-demographic data, open-ended questions and respondent feedback data were collated into the database also, in numeric coded and string formats.

6.2 Initial Analysis of the Psychometric Properties of the Scale

An initial analysis of the psychometric properties of the pilot scale was carried out using the methodology employed by the WHOQOL Group for the original WHOQOL-100 project (Bullinger et al, 1996; The WHOQOL Group, 1998). This methodology included analyses of missing values, response frequency, reliability (internal consistency), and correlation, all of which were performed at the level of the total pilot group ($N = 34$).

Missing Values

The rate of missing values within the pilot dataset was very low. For 38 items across 34 subjects, there were only 3 missing values, representing 0.2% of all values. Overall 92% of items had no missing values, and the remaining 8% of items had less than 3.0% missing values.

There were no missing values for items in the physical, social or environment domains. As shown in Table 6.10, the missing values occurred in relation to item 6 (spirituality) in the psychological domain; and items 30 (discrimination) and 34 (choice) in the hypothesised DX domain.

Table 6.10: Missing Values for Pilot Group

Domain	Item	Facet	All Subjects	
			N	*%*
Psychological	6	Spirituality	1	2.9
DX (Hypothesised)	30	Discrimination	1	2.9
	34	Choice	1	2.9
			3	*(N = 34)*

Although there were few missing values in this small dataset, those noted might reflect possible problems with items for the future, therefore the pilot forms were inspected to determine if any reason for the missing answers had been recorded. Two missing values related to assessments completed by clients responding directly: for item 6 (spirituality) it was noted that the client said the question was 'too hard'; and for item 30 (discrimination) the client's response was 'don't know'. The third missing value, for item 34 (choice), related to a staff proxy assessment, but no reason was recorded for this lack of response.

The guidelines set out by the WHOQOL Group suggested a conservative approach to dealing with such low rates of missing values (<10%) by replacement with the series mean. Therefore the subsequent reliability and correlation analyses were conducted on the dataset with missing values replaced.

Frequencies

Analyses of raw data response frequencies were carried out to examine the distribution of responses across the five point rating scale for each of the 38 items. The guidance contained in the Draft WHOQOL User Manual (WHO, 1998) suggests that if items have two or more adjacent scale points accounting for less than 10% of responses, this may indicate frequency problems. This may

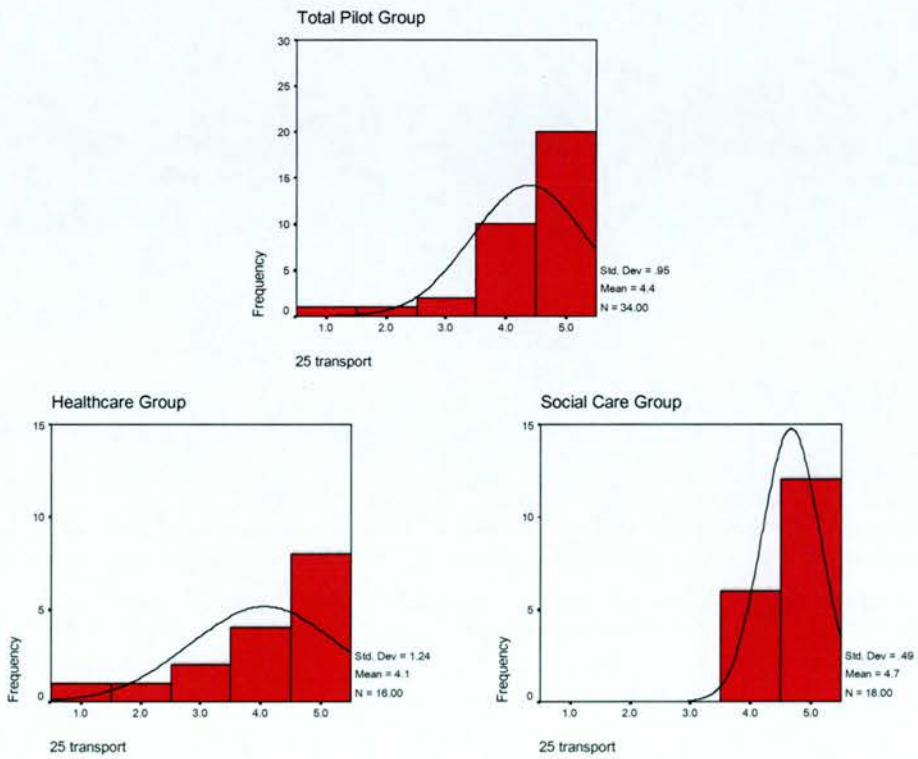
be indicative of a poor item, failing to discriminate adequately between sections of the target population for the instrument.

However, the response frequency distributions required to be approached with caution, as the distribution skew or kurtosis on some items might be an accurate reflection of the situation of ID clients within the sample (as well cared for and supported in staffed healthcare facilities or social care homes) rather than a signal of scale problems. For example, it would be expected that such supported living arrangements would provide safe environments (item 8); adequate social support (item 22); and appropriate levels of health and social care (item 24). Similarly, some frequency distributions may be artefacts of the two different response modes (direct and indirect) employed in completion of the pilot scale.

The response frequencies for the total pilot group are presented in full in Table A6.9 in Appendix 6.

For this pilot dataset, a potential frequency problem (i.e. a distribution with less than 10% responses on adjacent items) was noted for one item only, item 25 (transport). As shown in Table A6.9, 88.2% of the total pilot group rated their transport at the upper scale points of 4/5 *(ID rating: quite happy/very happy with transport)*, compared with only 5.8% responding at scale points 1/2 *(ID rating: very unhappy/a bit unhappy with transport)*.

Figure 6.1: Frequency Distributions for Transport (item 25)



However, as shown in Figure 6.1, the response distribution differed slightly for the two subgroups. The response distribution for the social care group was the most skewed, with 100% of responses at scale points 4/5, compared with only 75% for the healthcare group.

With appropriate caution in view of the small size of the pilot study and its constituent groups, the response distribution for the healthcare subgroup (showing a greater spread across the five scale points) seemed to suggest that those in receipt of healthcare held a range of views about their transport (and the responses of sections of this subgroup accounted for the responses shown at scale points 1-3 in the total group). In contrast, the response pattern for the social care subgroup (at the upper two scale points 4/5 only) seemed to suggest a greater degree of satisfaction with transport overall for those in social care facilities.

The ID wording of item 25 (transport) seemed to have retained adequate semantic equivalence with the original BREF item, and seemed to have been understood by participants. Despite this, the results of the frequency analysis appeared to suggest it might be a poor item, failing to discriminate between respondents. However, in the context of these specific participants, the high degree of satisfaction with transport seemed to be an accurate reflection of their situation, as all the clients in the social care group resided in facilities with access to dedicated transport (e.g. people carriers) and all of the clients in the healthcare group had access to some shared transport (e.g. mini-buses). On this basis, item 25 was not considered for further revision for the final version of the instrument.

Reliability

The reliability of the adapted WHOQOL-ID was examined using Cronbach alpha. This measure of reliability examines the internal consistency among items within a summated scale. Alpha values of 0.7 or higher are regarded as indicating an acceptable level of internal consistency; and alpha values of 0.6 or higher are considered satisfactory within the context of exploratory studies (Hair et al, 1998).

Corrected item-total correlations (the correlation of each item to the summated scale score calculated without the contribution of that item) were scrutinised also. A scale with good internal consistency might be expected to demonstrate item-total correlations of 0.4 or above. For the purposes of exploratory work, an acceptable threshold level of internal consistency might be set at 0.3; and item-total correlations below the threshold of 0.25 might be indicative of possible problems with an item (Kline, 1993).

A summary of the pilot scale reliability analysis, showing Alpha values, item-total correlations reaching 0.3 and 0.4 or higher (Pearson *r*), and possible problem items, is presented in Table 6.11.

Given the small size of the pilot study, with only 34 participants, it was not expected that threshold levels of internal consistency would be met in all cases. However, Cronbach alpha values for the environment domain and for the hypothesised additional domain DX reached 0.72, indicating good levels of internal consistency. The alpha values for the physical and psychological domains were lower at 0.5 and 0.6 respectively, but approached an acceptable level (which might be demonstrated with a larger sample).

Table 6.11: Reliability Indices for Pilot Scale ($N = 34$)

	Physical *7 items*	Psychological *6 items*	Social* *3 items*	Environment *8 items*	DX *12 items*
Cronbach Alpha Values	0.5036	0.5672	-0.1207	0.7153	0.7179
Number of Items $r > 0.40$	2	4	0	5	8
Number of Items $r > 0.30$	3	4	0	6	10
Possible Problem Items $r < 0.25$	3, 4, 15, 16	6, 11	20, 21, 22	8	34, 35

* Only 3 items, therefore Cronbach alpha may not be reliable

In contrast, the alpha values for the social domain were very poor. This finding needs to be interpreted with caution as the domain has three facets (personal relationships, social support and special relationship) and thus alpha is based on three item scores only. Four item scores would generally be regarded as the minimum required for assessing the internal consistency of a scale (Kline, 1983). However, even taking account of this, the very low alpha value suggested the possibility of problems with these social items.

In the physical domain, corrected item-total correlations reached 0.4 or higher on two items and 0.3 or higher on three items; in the psychological domain, corrected item-total correlations reached 0.4 or higher (and similarly 0.3 or higher) on four items; in the environment domain, corrected item-total correlations reached 0.4 or higher on five items and 0.3 or higher on six items; and in DX, corrected item-total correlations reached 0.4 or higher on eight items and 0.3 or higher on ten items. However, in the social domain, none of the item-total correlations reached either threshold, further suggesting the possibility of problems with these items.

Finally, possible problems (as defined by corrected item-total correlations below 0.25) were flagged on 12 items in the five domains: physical (four items), psychological (two items), social (three items), environment (one item), and DX

(two items). Ten of these items related to the original WHOQOL-BREF scale. Since the reliability of the BREF version of the instrument was already established (WHOQOL Group 1998a), the relatively low item-domain correlations obtained on these items in the pilot study may have been associated with item re-wording (possible inadequacy in relation to the level of cognitive ability of ID participants) or maintenance of semantic equivalence (possible simplification achieved at the expense of precision of meaning) in the adapted WHOQOL-ID version of the instrument. Therefore, these possible problems items could be reviewed to determine the potential for minor revisions (e.g. wording adjustment, or addition of a prompt or example).

The impact of all possible problem items (including the two items in domain DX) on the relevant scale alpha value was examined also. This indicated that for nine items, there would be little (or only moderate) impact on the scale alpha value if the item were deleted; but for four items (6, 20, 21 and 22) a more major impact was evident, increasing the alpha value by 0.1 to 0.8 (rounded values) if the corresponding items were to be deleted from the scale. This confirmed that such items would merit review and revision in order to improve the reliability of the WHOQOL-ID.

Correlations

In addition to the corrected item-total correlations undertaken as part of the scale reliability analyses, further correlations were carried out to determine whether any WHOQOL-ID item loaded higher on another domain than its own predicted domain. This was relevant to the reworded items within the four original WHOQOL domains (physical, psychological, social and environment), but of particular importance in terms of the 12 items in the hypothesised domain DX. It was possible that one or more of these new ID items might load higher on one of the four base domains (for example the psychological or environment domains) rather than on the predicted domain of DX. This would suggest that such items might be more appropriately placed in these domains, or might be tapping quality of life facets already included in the scale.

The pattern of significant item-domain correlations (as defined by $r > 0.4$) across domains was inspected also. It was possible that some items might load at a high level on the predicted domain, but show a significant loading on one or more additional domains also. Some item-domain cross-correlations would be predictable, given the global nature of the quality of life scale and the definitions of constituent facets (items): for example, item 10 (energy) loading on both its own physical domain and on the psychological domain. However, it was possible that some items might show significant but non-predicted associations with a domain on which the item should not load, flagging possible problems with that item.

As such problem items were excluded from the original WHOQOL-100 and the BREF in the process of scale development, non-predicted loadings would not be expected on items in the four base domains of the adapted WHOQOL-ID. Thus any significant non-predicted correlations identified on base domain items might relate to specific (identifiable) characteristics of the pilot study participants, or might flag problems associated with item re-wording or semantic equivalence. However, as the new items in domain DX had not been subject to previous psychometric evaluation, significant non-predicted loadings might identify possible problem items requiring revision for, or possibly warranting exclusion from, the final scale.

The scale correlations for the total pilot group are presented in full in Table A6.10 in Appendix 6.

Item-domain correlations

As shown in Table A6.10, all but two items associated with the four base domains (physical, psychological, social and environment) showed the highest correlation with the predicted domain. The two exceptions were item 18 (work) which correlated highly with the predicted physical domain ($r = 0.55$), but also correlated at a similar levels with the social ($r = 0.56$) and environment ($r = 0.59$) domains; and item 8 (safety) which correlated at a relatively low level with the predicted environment domain ($r = 0.29$), at a similar level with the physical domain ($r = 0.31$), and at a higher level with the psychological domain ($r = 0.43$). In addition, items 3 (pain) and 6 (spirituality), which did demonstrate the highest correlation with the predicted domains, demonstrated relatively lower item-domain correlations ($r < 0.4$) than the other items. Items 3 and 6 also demonstrated poor corrected item-total correlation when contribution to their respective domains was excluded.

In domain DX, nine out of twelve items showed the highest correlation with the predicted domain. Of the three exceptions, item 27 (stigmatisation) showed similar levels of correlation with both the predicted DX ($r = 0.42$) and with the non-predicted social domain ($r = 0.44$). However, item 34 (choice) showed a very poor correlation with the predicted DX ($r = 0.14$), and demonstrated higher correlations with every other domain, the highest of which was with the non-predicted environment domain ($r = 0.43$). Similarly, item 35 (self advocacy) showed a very poor correlation with the predicted DX ($r = 0.17$), and demonstrated higher (but still relatively low) correlations with the non-predicted psychological ($r = 0.27$) and environment ($r = 0.29$) domains. Items 34 and 35 also demonstrated poor corrected item-total correlation when contribution to domain DX was excluded.

The findings of the analysis of item-domain correlations were approached cautiously, given the sample size, but seemed to confirm the problematic nature of some items.

Cross-correlations

In the four base domains, thirteen items showed significant cross-correlations (as defined by $r > 0.4$) with other domains, although all but two of these correlated at a higher level with the predicted domain. In the physical domain, items 10 (energy) and 16 (sleep) cross-correlated with the environment domain; item 17 (activities of daily living) cross-correlated with the psychological domain; and item 18 (work) loaded significantly with the environment domain. In the psychological domain, item 7 (thinking) loaded significantly on the physical domain; and item 11 (body image) cross-correlated with the environment domain. In the social domain, item 20 (personal relationships) cross-correlated with all the other domains, including DX; and item 22 (social support) cross-correlated with the psychological domain and DX. Finally, in the environment domain item 8 (safety) cross-correlated with the psychological domain; item 13 (information) cross-correlated with DX; items 14 (leisure activities) and 25 (transport) cross-correlated with the psychological domain; and item 23 (home) showed significant loading on both the physical and social domains.

In domain DX, four further items also showed significant cross-correlations (as defined by $r > 0.4$) with other domains. Two of these demonstrated higher correlations with the predicted domain: item 29 (ridicule), which loaded significantly on the social domain; and item 38 (acceptance), which cross-correlated with the environment domain. However, item 34 (choice) showed significant cross-correlations with all four other domains, which were higher than that achieved on DX; and item 35 (self advocacy) showed significant cross-correlations with three other domains, which were higher than that achieved on DX.

In relation to the original base domains and DX, the relationship between the majority of these items and their predicted and associated domains was explicable (and, to varying extent, predictable) in terms of item content, facet definition or the characteristics of the pilot study participants.

Overall, the correlation analysis seemed to suggest that the nine out of the twelve new items that correlated highest with the predicted DX represented additional quality of life themes and were not tapping facets already included in the scale. In addition, one further item (item 29, ridicule) contributed significantly to DX, despite demonstrating similar (explicable) levels of correlation with the social domain. However, the pattern of item-domain correlations and cross correlations suggested that items 34 and 35 demonstrated a poor fit with DX and lacked reliability in relation to the scale overall.

Summary of Possible Problem Items

A summary of the possible problem items identified in the initial analysis of the psychometric properties of the pilot scale is presented in Table 6.12.

As missing values were noted on three items only, all of which were < 3.0%, no particular problems were identified from this preliminary analysis. Similarly, frequency problems were noted on one item only, and this could be accounted for in relation to the specific participants of the pilot study. However, 12 possible problem items were identified from the reliability analysis, five of which were flagged from the correlation analysis also, as shown in Table 6.12.

Table 6.12: Summary of Possible Problem Items from Psychometric Analysis

Domain	Item	Facet	Reliability	Correlations
Physical	3	Pain	X	X
	4	Medication	X	
	15	Mobility	X	
	16	Sleep	X	
Psychological	6	Spirituality	X	X
	11	Body image	X	
Social	20	Personal relationships	X	
	21	Special relationship	X	
	22	Social support	X	
Environment	8	Safety	X	X
DX	34	Choice	X	X
	35	Self advocacy	X	X

Blue denotes items for major revision Red denotes items for deletion

As the pilot study was small, these possible problem items require to be viewed with some caution. In the physical domain, all the featured items showed poor corrected item-total correlations; but overall, the resultant impact on the scale alpha was relatively minor. Item 3 (pain) showed a relatively low correlation with the predicted domain, but did not correlate higher on any non-predicted domain. Similarly, item 11 (body image) in the psychological domain, and item 8 (safety) in the environment domain, both showed poor corrected item-total correlations but the resultant impact on the respective scale alphas was relatively minor. Item 8 showed relatively low correlation with the predicted domain also, but the slightly higher correlation with the non-predicted psychological domain was explicable in relation to the of the ID client group. For all these items, the problems noted may have been artefacts of the small numbers, and the characteristics of the clients, rather than indicators of major item-scale flaws. However, the remaining items were of greater concern.

For item 6 (spirituality) the poor corrected item-total correlation and the relatively low correlation with the predicted domain, were associated with possible issues about item intelligibility, as 17% of the clients responding directly provided feedback that this was a 'hard' question. This suggested that the item required substantial revision.

Items 20 (personal relationships), 21 (special relationship) and 22 (social support) all showed poor corrected item-total correlations and their impact on the scale alpha was more marked. The lack of reliability of Cronbach alpha on scales with fewer than four items has already been noted, and in the context of a small pilot sample, it was difficult to interpret the significance of these findings. Furthermore, all three items showed moderate to high correlations with the predicated social domain and an unremarkable pattern of lower correlations with other domains. However, it was thought that the wording of items 20 and 21 could be improved and these items were marked for revision also.

Finally, items 34 (choice) and 35 (self-advocacy) were particularly problematic. Both items showed poor corrected item-total correlations, but the resultant impact on the scale alpha was relatively minor overall; however, both items demonstrated almost negligible correlation with the predicted domain DX, and item 35 (self-advocacy) showed poor to negligible correlations with all the other domains also. Item 34 (choice) showed moderate correlations with the non-predicted social and environment domains, but this may have been an artefact of the associated prompt designed to clarify the nature of 'big choices', as this specifically mentioned '*where to live, who to live with etc.*'. Poor wording, conceptual difficulty and salience were all considered as possible issues in relation to these items. However, in view of the extent the correlation problems, and as both the facets represented by these items (autonomy and advocacy) contained one other more robust item which had not been flagged as a possible problem in any of the analyses, items 34 and 35 were marked for deletion from the revised scale.

6.3 Other Initial Analyses

Open Questions

The qualitative data collected in response to the open-ended questions could not be subjected to the same systematic analysis as the quantitative WHOQOL-ID items. However, there were no missing values for any of the set of four questions, which suggested that both clients and staff proxies were able to respond to these questions readily, despite the different 'open' format.

The responses provided were varied, but amenable to simple categorisation for analysis. Respondents cited social and leisure activities (29%), relationships (26%) and home (26%) most frequently as the 'best' thing in life. Similarly respondents rated home/current placement (21%), lack of activities (15%), poor relationships (15%) and lack of autonomy (12%) most frequently as the 'worst' thing in life. Respondents mentioned home most often as the aspect of life they wished to 'change' (30%), followed by relationships (15%). Finally, half of all participants (69% of the healthcare subgroup and 33% of the social care subgroup) mentioned an ambition to move home in respect to the question about

the future. These data were very similar to the quality of life themes generated by clients in the focus groups (and rated as the most important themes in their lives), and this provided a preliminary indication of validity.

Assessment Duration

The Draft WHOQOL User Manual (WHO 1998) notes that self-administration of the WHOQOL-100 may take around 30 minutes, but that longer would be required for the interview administered form (e.g. 40-90 minutes for people with literacy problems). The shorter WHOQOL-BREF was selected as the base instrument for adaptation for adults with intellectual disabilities, in order to take account of the characteristics of the ID population (e.g. possible limitations of attention span etc.) in relation to the longer measure. For this reason, assessment duration for the new WHOQOL-ID was of particular interest.

In all cases, the measure was completed in one session only, although all prospective respondents were offered the opportunity of more than one session if required.

The time taken for the formal aspects of the assessment interview (excluding informal engagement and conversation to establish rapport etc) was noted for all respondents. The mean assessment duration for the total pilot group was 23 minutes (*SD* 9 minutes). However, as shown in Table 6.13, the assessment took longer with clients than with proxy staff: the mean completion time for clients responding directly was 31 minutes (range 20-45) and the mean completion time for proxy staff was 19 minutes (range 12-30). For clients and staff completing the assessment together (with staff in a supportive role, or acting as a channel of communication) the mean completion time was 25 minutes (range 15-35).

Table 6.13: Assessment Duration (minutes)

Group	*N*	Range	Mean	*SD*
Client Direct	11	20 - 45	31.4	± 8.97
Client + Staff Combined	2	15 - 35	25.0	± 14.14
Staff Proxy	21	12 - 30	18.7	± 4.98
Total Group	34	12 - 45	23.2	± 8.98

Pro-rata, these data were comparable with the suggested completion times (the expected assessment duration for 42 questions, 38 core Likert scale items, and four open-ended questions, would be 17-38 minutes), and in combination suggested that the WHOQOL-ID was viable as an instrument for adults with intellectual disabilities.

6.4 Feedback from Participants

Feedback on the experience of completing the WHOQOL-ID was collected from 25 participants: 12 clients, 11 of whom had responded directly to the assessment, plus one client who had responded in combination with staff; and 13 proxy staff who had responded on behalf of a total of 22 clients. The majority of proxies (nine) responded on behalf of one client only, but two proxies each responded for two clients; one proxy responded for three clients, one of whom had responded to the main assessment in combination with that member of staff; and one proxy responded on behalf of six clients. A summary of the participant feedback is shown in Table 6.14.

Table 6.14: Summary of Participant Feedback (%)

Feedback Issues	Clients (*N* = 12)			Proxy Staff (*N* = 13)		
	Yes	No	Don't Know	Yes	No	Don't Know
Any Q hard to understand?	75.0	25.0	-	46.2	53.8	-
Any Q not relevant?	-	91.7	8.3	38.5	61.5	-
Faces helpful?	100	-	-		*Not applicable*	
Anything missing?	8.3	91.7	-	53.8	46.2	-

'Hard' and 'Best' Questions

All participants were asked if any questions were hard to understand, and 75% of clients and 46% of staff responded in the affirmative. In response to the follow up about which were 'hard' questions, the majority of participants who responded mentioned only one item, or reported that they could not remember. The feedback on 'hard' questions is presented in full in Table A6.11 in Appendix 6, and a summary of the items mentioned more than once is shown in Table 6.15.

Table 6.15: Summary of Feedback – 'Hard' Questions

Domain	Item	Facet / Q Topic	All Respondents	
			N	%
Physical	3	Pain	2	8
Psychological	6	Spirituality	2	8
Environment	9	Physical environment	2	8
DX	30	Discrimination	2	8
Open Q	4	Ambition	2	8
			(*N* = 25)	

As shown in Table 6.15, five items were cited as 'hard' by two respondents (8%); but no item was mentioned by more than two respondents. One item from three of the core domains was mentioned, one item from the additional domain DX was mentioned, and the open question about what the client wished for the future was also cited as difficult.

The parallel question about which were the good (or best) questions received a greater response. The feedback on the 'best' questions is presented in full in Table A6.11 in Appendix 6, and the items mentioned by at least 10% of respondents are summarised in Table 6.16.

Table 6.16: Summary of Feedback – 'Best' Questions

Domain	Item	Facet / Q Topic	All Respondents	
			N	%
Psychological	26	Negative feelings	5	20
Social	21	Special relationship	3	12
DX	27	Stigmatisation	4	16
	28	Victimisation	5	20
	29	Ridicule	4	16
	30	Discrimination	5	20
	31	Enabling	5	20
	32	Empowerment	5	20
	33	Autonomy	5	20
	34	Choice	5	20
	35	Self advocacy	5	20
	36	Advocacy	5	20
	37	Respect	4	16
	38	Acceptance	4	16
Open Q	1	Best	3	12
	2	Worst	3	12
	3	Change	3	12
	4	Ambition	3	12
			(*N* = 25)	

As shown in Table 6.16, in the core domains, item 26 (negative feelings) and item 21 (special relationship) were mentioned as 'good or best' questions, and in respect of both, all the respondents were proxy staff. These staff indicated they were in favour of seeking information on such facets, which in their experience, were not approached directly in the assessments used in their facilities. Similarly, the open questions received favourable mention, again from staff proxies. Finally, the items cited most often in the 'best question' category were the set of items that comprised the new domain DX, with between 16% and 20% of participants (again staff) rating these as good questions.

As shown in Table A6.11, clients identified a number of items as 'good' questions also; but only one client mentioned each cited item (corresponding to only 4% of the total respondents). The items mentioned as 'good or best' by clients proved revealing as they mirrored many of the categories of answers given to the open questions i.e. clients seemed to like the questions that asked about the things that they cited as the best or worst things in their lives also e.g. home, leisure activities, and relationships. This suggested that for these clients, salience was an important criterion in judging 'good' questions.

Relevance and Fit with Clients' Lives

As shown in Table 6.14, the majority of participants (92% of clients and 62% of proxy staff) thought the questions they had been asked were relevant and made sense in relation to the lives of clients. Clients did not mention any question as irrelevant, but one staff proxy mentioned item 3 (pain), one mentioned item 12 (finance), one mentioned item 23 (home), and two cited item 24 (health and social care). However, it was not clear why proxy staff considered these items to have poor fit, or to be irrelevant for clients. It was possible that these staff had reservations about the degree of understanding clients might have of some items (e.g. finance); it was possible also that staff perceived these items to be 'care provider' issues, and hence less directly relevant to clients; alternatively, they may have had concerns that gathering information about these areas was straying into provider territory, and assessing the care situation rather than the clients.

Smiley Faces

Clients who responded directly were asked if the 'smiley faces' used to augment the response scales helped them to answer the questions. As shown in Table 6.14, 100% of clients endorsed the smiley faces as helpful.

Missing Facets

All participants were asked if anything was missing from the WHOQOL-ID i.e. other questions required to achieve a comprehensive assessment of the quality of life of adults with intellectual disabilities. As shown in Table 6.14, 92% of clients and 54% of proxy staff thought that nothing was missing from the scale. One client (8%) responded that something was missing, and suggested that the scale should include questions about 'problems in your life'. Six staff proxies (46%) responded that something was missing, and suggested a number of additions, most of which were either very specific (e.g. quality of food, quality and appropriateness of day centre activities) or already covered by the pilot instrument to some extent (e.g. finance, availability of support).

General Comments

Finally, all participants were invited make general comments about the instrument and their experience of questionnaire completion. 67% of clients and 46% of staff provided such comments, the content of which is summarised in Table 6.17.

Table 6.17: Summary of Feedback – General Comments

End of Questionnaire Comments	Clients (*N* = 12)		Staff (*N* = 13)	
	N	%	*N*	%
Questionnaire fine / good	4	33.3		
Questionnaire enjoyable	2	16.7		
Questions easy and not embarrassing	1	8.3		
Questions on private things hard	1	8.3		
Questionnaire hard for severe ID			1	7.7
Hard to answer for client			2	15.4
Useful to think about client			1	7.7
Helpful, but religion Q hard			1	7.7
How honest will staff be in responding?			1	7.7
No comments	4	33.3	7	53.8

Apart from the category of 'no comments', there was little overlap between the client and staff responses.

The majority of the clients who commented made favourable remarks about the questionnaire, e.g. 'all the questions were fine'; 'the questions were easy and not embarrassing'; but one client commented that 'questions on private things [not elucidated] were hard'. The impression gained during the client interviews was that clients enjoyed the experience of completing the questionnaire (one individual made that specific comment) and particularly enjoyed expressing their own views about their lives.

The comments of proxy staff were more varied. One proxy staff remarked that the questionnaire was useful as it had made them think more about their client and specifically that client's perspective on life; in contrast, reflecting on the experience of being a proxy, two staff commented that it was 'hard to answer for a client' and a third mentioned the difficulty of responding on behalf of a client with severe intellectual disabilities. One proxy staff found the questionnaire helpful, but noted that the item on religion (item 6) was hard to answer. Finally, one person speculated about how 'honest' staff might be in providing proxy responses to items that might reflect (either positively or negatively) on the care setting or the staff team.

Summary of Feedback

The staff feedback was compared with the outcome of the initial psychometric analysis to determine if respondents flagged the psychometrically poor items as problematic from their perspective also.

The feedback on 'hard' questions provided additional support for the need to revise item 6 (spirituality). Although only 2% of respondents overall identified this as a difficult item, all were clients; they represented 17% of the total group of clients responding directly; and this item was cited by the highest proportion of clients identifying any item as hard.

For the relationship items 20 (personal relationships) and 21 (special relationship) feedback was more equivocal. Item 20 was identified as one of the 'best' questions by clients, and as one of the 'hard' questions by staff; and both clients and staff identified item 21 as one of the 'best' questions. Despite this, it was thought that the wording of both could be improved.

Finally, items 34 (choice) and 35 (self advocacy) were rated by 38% of staff as amongst the 'best' questions. However, this endorsement was in the context of the 'set' of DX items, and the extent to which these items may have been subject to set effects, rather than being rated as individual items, is not clear. For item 34, there was anecdotal evidence that clients tended not to have the opportunity for 'big choices' (as tapped by this item). Similarly, for item 35, there was an implicit suggestion that some members of staff teams might be less than supportive of clients' attempts at self-advocacy. Neither item was identified by any participant as lacking in fit with clients' lives, but to do so may have been contrary to underlying service principles.

Overall, the small field trial of the pilot instrument showed that both clients with the capacity to respond directly, and proxy staff, were able to complete the WHOQOL-ID and to express views on constituent items and response format. In combination, the outcome of the psychometric analysis, the participant feedback, and the experience gained through administration of the pilot WHOQOL-ID by interview, provided useful information for revision of the scale for further, more extensive, field trial within the main study.

6.5 Scale Revisions and Proposed Final Instrument

The information derived from the pilot trial provided the framework for the review, revision and refinement of the WHOQOL-ID, and the subsequent design of the proposed final instrument. Changes to the pilot instrument were introduced in three main areas. In order of appearance these were: introductory socio-demographic questions; main scale items, associated prompts and subsidiary open-ended questions; and general end of scale items.

Socio-demographic questions

Two minor revisions were made to the socio-demographic questions included in the section 'ABOUT YOU' at the start of the WHOQOL-ID. Firstly, the response choices available for the item on education were expanded to include a sixth category 'Not Known' to reflect the absence of knowledge of educational background for many people with intellectual disabilities. Secondly, the three-part item on disability (introduced specifically for the ID population) was deleted, as attempts to capture ID clients' perceptions of the presence of disability had proved difficult and potentially unreliable.

Item revision

A number of items were subject to major revision (e.g. re-wording to enhance intelligibility or remove ambiguities); some items were subject to more minor revision or refinement (e.g. to improve wording); some additional item prompts were introduced to illustrate items or aid clarity of meaning; some existing prompts were revised; and the format of item prompts was standardised as far as possible. The full set of item revisions (showing a comparison of pilot and revised items) is presented in Table A6.12 in Appendix 6, and described by domain or section below.

Physical domain

Three very small modifications were made to items in the physical domain. These are highlighted[1] in Table 6.18.

Table 6.18: Revision of Pilot Items – Physical Domain

No.	Facet	Pilot WHOQOL-ID Item	Revised WHOQOL-ID Item
15	Mobility	Is it easy or difficult for you to get around in the house and outside? *Prompt: Do you have any physical problems that make it hard for you to get around?* (Note: walking aid or wheelchair if used.)	Is it easy or difficult for you to get around in the house and outside? *For example, do you have any physical problems that make it hard for you to get around?* (Note: walking aid or wheelchair if used.)
17	ADL	How happy or unhappy are you with your ability to do everyday things? *Hint: Thinking about looking after your self, washing, dressing, eating.*	How happy or unhappy are you with your ability to do everyday things? *For example, looking after your self, washing, dressing, eating.*
18	Work	How happy or unhappy are you with your ability to do your work, or to do your daytime activities?	How happy or unhappy are you with your ability to do your work, or your daytime activities?

[1] Wording alteration highlighted in red for pilot item and blue for revised item

Minor wording changes were made to the prompts for items 15 (mobility) and 17 (ADL); and the wording of item 18 (work) was simplified, slightly reducing the item length.

Psychological domain

In the psychological domain, item 6 (spirituality) required more substantial modification. As shown in Table 6.19, the item was simplified and reference to 'making life worthwhile' was deleted, as this concept had proved difficult for clients. In addition, a new prompt in the form of an illustrative example was added in an effort to enhance item intelligibility.

Table 6.19: Revision of Pilot Items – Psychological Domain

No.	Facet	Pilot WHOQOL-ID Item	Revised WHOQOL-ID Item
6	Spirituality	Is god (or are religious things) important in your life? Do these things help to make your life worthwhile?	Is god (or are religious things) important in your life? *For example, do you go to church?*

Social domain

In the psychological domain, two items required substantial modification. It was recognised that item 20 (personal relationships) was poorly worded, potentially encompassing three sets of personal relationships, each of which might draw a different response. Therefore the item was simplified by reducing the relationships mentioned to one category only, as shown in Table 6.20.

Table 6.20: Revision of Pilot Items – Social Domain

No.	Facet	Pilot WHOQOL-ID Item	Revised WHOQOL-ID Item
20	Personal relationships	How happy or unhappy are you with the way you get on with your friends, your family and the people you live with?	How happy or unhappy are you with the way you get on with the people you live with?
21	Special relationship / Sexual activity	Do you have special, close, or physical (sexual) relationship with someone? • If yes, how happy or unhappy are you with that relationship? • If no, how happy or unhappy are you about this?	Do you have a very close or special relationship with someone? • If yes, how happy or unhappy are you with that relationship? • If no, how happy or unhappy are you about this?

The decision about which element to retain was guided by the fact that not all ID clients might be in contact with family members e.g. as a result of current or

former institutionalisation; and that some ID clients use the term 'friends' for paid care staff, as well as for those with whom they have informal and reciprocal personal relationships i.e. friendships in the usual sense of the word. It was considered that the phrase 'the people you live with' was less ambiguous and open to inclusion of fellow residents or staff (as determined by the mind set of clients); and that potentially, such relationships might have a crucial impact on the quality of life of ID clients who might lack the capacity to, or be prevented from, changing their circumstances.

For item 21 (special relationship) it was possible that the remaining reference to sexual activity (from the original BREF item), albeit as an adjunct to the wider concept of a 'special' relationship, may have been confounding response patterns. As with the general population, not all ID clients may have experience of sexual activity; but unlike other mainstream groups, many ID clients additionally live in situations in which the physical expression of relationships is discouraged, or proscribed outside the confines of marriage. Therefore, the words physical and sexual were deleted from the item, and the emphasis was placed on the more inclusive 'special' or very close relationship.

Environment domain

Changes were made to four items in the environment domain and these are highlighted in Table 6.21.

Table 6.21: Revision of Pilot Items – Environment Domain

No.	Facet	Pilot WHOQOL-ID Item	Revised WHOQOL-ID Item
8	Safety	Do you feel safe or unsafe in your daily life?	Do you feel safe or unsafe in your daily life? *For example, at home and in your local neighbourhood*
9	Physical environment	Do you think this is a healthy or an unhealthy area/part of town to live in? *Hint: Thinking about the weather, the noise, the traffic etc*	Do you think this is a healthy or an unhealthy area/part of town to live in? *For example, thinking about the noise, the traffic, the pollution, the weather etc*
14	Leisure activities	Is it easy or difficult to get the opportunity for leisure activities? *Prompt: Is it easy or difficult to get the chance to do things you like in your spare time?*	Is it easy or difficult to get the opportunity for leisure activities? *Prompt: Is it easy or difficult to get the chance to do things you enjoy in your spare time?*
23	Home	How happy or unhappy are you with the place you live in? *Hint: Thinking about what your home is like, the area you live in etc.*	How happy or unhappy are you with the place you live in? *For example, thinking about what your home is like, the area you live in etc.*

Minor modifications were made to the wording of prompts for items 9 (physical environment) and 23 (home); and a prompt in the form of an illustrative example was introduced for item 8 (safety). In addition, the word 'like' was replaced by 'enjoy' in item 14 (leisure activities) to reduce possible confusion in meaning between 'doing things you like' as in 'doing what you want', and the intent of the item i.e. 'doing things you enjoy'.

Domain DX

Changes were made to three items in DX; and two items were deleted from the scale. The two deleted items were 34 (choice) and 35 (self-advocacy), and both were dropped as a result of poor psychometric performance (as described fully section 6.2).

Table 6.22: Revision of Pilot Items – Domain DX

No.	Facet	Pilot WHOQOL-ID Item	Revised WHOQOL-ID Item
36	Advocacy	Do you feel you have someone to stand up for you, or to support you?	How often do you feel you need someone to stand up for you, or to support you?
37	Respect	Do you feel that other people take you seriously? *Prompt: For example do other people take notice of your views and listen to what you have to say about things or do they ignore you?*	Do you feel that other people take you seriously? *For example, do other people take notice of your views and listen to what you have to say about things or do they ignore you?*
38	Acceptance	Overall, how much do you feel that people accept you?	Overall, do you feel that people accept you?

Minor modifications were made to the prompt for item 37 (respect) and the wording of items 36 (advocacy) and 38 (acceptance), as shown in Table 6.22. For item 36 (advocacy) the item was reworded to clarify item intent, which was to capture *how often* someone might feel the need for an advocate, rather than simply whether such a person was available. For item 38 (acceptance) the item was reworded to avoid confusion between the extent to which someone might feel accepted (e.g. a little, a lot) and *how often* acceptance was felt (e.g. sometimes, always).

Open-ended questions

Finally, a minor modification was made to the wording of the open-ended question about 'change', to promote consistency with the related questions on 'best' and 'worst' things in life; and a small change in wording was made to the prompt for the 'future / ambition' item to promote clarity of meaning. These modifications are highlighted in Table 6.23

Table 6.23: Revision of Pilot Items – Open Ended Questions

No.	Facet	Pilot WHOQOL-ID Item	Revised WHOQOL-ID Item
(c)	Change	Is there anything you would like to change about your life?	Is there anything you would like to change about your life now?
(d)	Future / Ambition	What would you like for the future? *Prompt: what would you like to happen next?*	What would you like for the future? *Prompt: what would you like to happen next in your life?*

General Items

Two small modifications were made to the general end of scale items. Firstly, space was provided to record whether the scale was completed by direct (client) or indirect (proxy) interview, and to collect information about the identity of proxy respondents. Secondly, space was provided to record the identity of the interviewer and the date of assessment interview.

Proposed Final Instrument

Following the development work carried out in the field trial, and the revisions of the pilot scale described, the proposed final version of the WHOQOL-ID was further tested as part of the main study. The final main study version of the instrument is presented at A6.13 in Appendix 6.

Chapter 7

Subsidiary Study: Survey of Community Accommodation

During the preparation of the pilot and main studies on the quality of life of adults with intellectual disabilities, a large housing agency expressed interest in an allied aspect of the research: the alternative accommodation to which the former hospital residents in the index community group had transferred. Therefore, a subsidiary study on this aspect of ID client's experience of community living was incorporated into the overall framework of the research.

The objectives of the subsidiary study were to:

1 Carry out a brief survey of the characteristics (type and design) of the accommodation in which the ID clients in the community cohort resided.

2 Collect and analyse the views of senior project staff on the quality of the accommodation, its suitability for the resident group, and its effectiveness at meeting client's needs.

3 Identify those aspects of the accommodation associated with positive or negative outcomes (if any) for clients.

7.1 Design and Methodology of Survey

A survey format was drawn up in concert with the housing agency, the design and content of which reflected the specific contemporaneous interests of the agency and its planning officers.

The accommodation survey was carried out as an adjunct to the main study, prior to the collection of quality of life data on the community clients, and was subject to similar essential ethical safeguards with regard to voluntary participation, informed consent and confidentiality.

The prior agreement of the community care providers (at Director level) was sought to approach the 'project manager' i.e. the person in immediate day-to-day charge of each community project to provide information to complete the survey. These project managers were in receipt of full information about the research, as part of the main study procedure (see Chapter 8), and they were afforded the opportunity to look over the accommodation survey forms prior to completion. In total, 51 community projects were approached to participate in the accommodation survey, and by agreement with the appropriate managers, all were included subsequently.

Measures

The data collected in this small study included brief details of the community projects and the related accommodation packages; and a survey of the views of project of managers about the quality and effectiveness of the accommodation e.g. in meeting clients needs, assisting care and support, and achieving community integration. No data were collected on individual residents as part of the survey.

The custom designed measures for the study comprised an accommodation checklist (Project Description Form, shown at A7.1 in Appendix 7) and a brief accommodation questionnaire (Housing Questionnaire, shown at A7.2 in Appendix 7) that included both open-ended questions and semi-structured items rated on a Likert type scale.

Procedure

The two survey forms were completed by interview, in the context of individual meetings arranged to suit the convenience of each designated project manager. To ensure a consistent approach, all interviews were carried out by the same (principal) researcher. Informants were invited to provide information and offer views from their own perspective and from other members of the regular staff team (if known). They were requested to confine their responses to issues related to that specific project (not including any other projects for which they might have responsibilities) and were cautioned to avoid identifying any client by name when providing project related information.

7.2 Characteristics of the Projects

The 51 community projects that supplied information as part of the subsidiary study were managed by 12 different organisations, and provided accommodation and social care for over 200 adults with intellectual disabilities. As shown in Table 7.1, the majority of the projects were provided by voluntary or housing organisations (51%), and the remainder were managed either by a religious order (29%) or a private provider (20%).

Table 7.1: Projects by Provider Type

Provider Type	Projects (*N* = 51)	
	N	%
Voluntary / Housing Organisation	26	51.0
Private Provider	10	19.6
Religious Order	15	29.4

Project Duration

All but one project opened between 1995 and 1999 during the main period of the hospital closure and related community care programmes. Project duration at the time of the survey ranged from two to thirteen years, with a mean duration of 3.8 years (*SD* 1.9).

The duration of the community projects since first opening is presented in Table 7.2. As shown, 67% of the projects had been open for four years or less and 33% had been open for five or more years.

Table 7.2: Duration of Community Projects at 2001

Project Duration (Rounded years)	Projects (*N* = 51) *N*	%
2	13	25.5
3	15	29.4
4	6	11.8
5	12	23.5
6	4	7.8
13	1	2.0

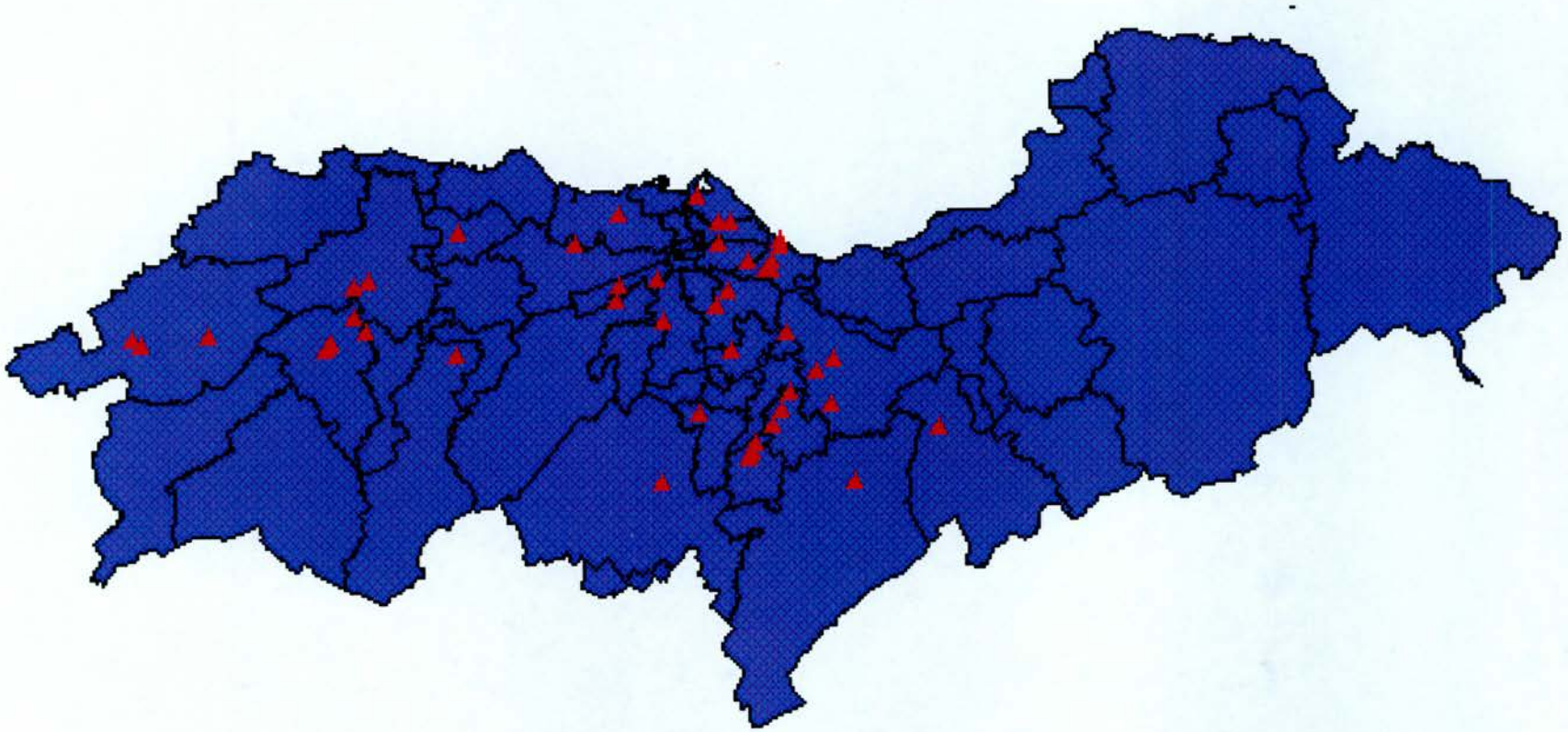
Location

The community-based social care projects were situated within the boundaries of three local authorities within an NHS Area comprising four such authorities. Historically, three learning disabilities hospitals were situated in the region: the city and west were the main catchment areas of the largest learning disabilities hospital which was located on the western edge of the city; and the south and east were separate catchment areas for two smaller locally-based hospitals. The index group of community clients in the main study had resided formerly in two of these three hospitals only (in the city and the south), and as part of these hospital's linked resettlement programmes they had re-located back to these original areas predominantly. For this reason, no projects within the study were located in the east local authority area, which had been the subject of an earlier and unrelated community care programme.

Of the 51 community projects, 20 (39%) were located in the main city area, 12 (24%) were in the western area, and the remaining 19 (37%) were in the southern area of the region. Approximately 88% of the projects were in urban or suburban communities and 12% were in rural or semi-rural settings.

The exact location and geographical spread of the community projects is represented on the regional map in Figure 7.1.

Figure 7.1: Location and Geographical Spread of Community Projects



Size

The projects reflected a variety of shared or grouped living arrangements from houses to clusters of individual flats. The smallest project provided three residential places, the largest project had nine places, and the mean project size was 5.3 (*SD* 1.68). The number and proportion of projects by size (number of places) is presented in Table 7.3. As shown, in Table 7.3, 67% of the projects had five places or fewer and 33% had six or more places.

Table 7.3: Projects by Number of Places

Places	Projects (*N* = 51)	
	N	%
3	7	13.7
4	11	21.6
5	16	31.4
6	7	13.7
7	1	2.0
8	7	13.7
9	2	3.9

Accommodation Type

Almost all the projects (98%) were based on regular housing stock, but one project (2%) was part of a larger residential care home. As shown in Table 7.4, most of the projects were accommodated in flats (16%), semi-detached houses (26%), bungalows (37%) and detached houses (14%).

Table 7.4: Projects by Accommodation Type

Accommodation Type	Projects (*N* = 51)	
	N	%
Apartment / Flat	8	15.7
Semi-detached house	13	25.5
Bungalow	19	37.3
Detached house	7	13.7
Farmhouse	2	3.9
Cottage	1	2.0
Residential Home	1	2.0

Overall, 59% of projects were located in ground floor only dwellings, 39% were accommodated in dwellings with both ground and first floors, and one project (2%) was located in a first floor flat.

Accommodation Design

Twenty-three projects (45%) were based in new purpose built accommodation; 18 projects (35%) were in accommodation specially adapted for the client group; and 10 projects (20%) had made use of regular 'off the shelf' housing. Five of the projects in adapted accommodation, and one in regular housing, had extended the basic building as part of the preparation for client use.

Accessibility

Twenty-two projects (43%) were barrier-free and accessible to those with physical disabilities (e.g. wheelchairs) throughout. A further six projects (12%) had partial disabled access e.g. on the ground floor only. Eleven projects (22%), which were a mix of new, adapted and regular housing, had external ramp access also. Twenty-one projects (41%) had one or more wheelchair-accessible low surfaces included in the design of the kitchens. In contrast, two projects (4%) made use of 'gates' to prevent client access to the kitchen area.

Bathrooms

The projects provided a range of bathroom types. Thirty-two projects (63%) had regular bathrooms, of which 75% had one only, 16% had two, 3% had three, 3% had four and 3% had five. Twenty-six projects (51%) had 'assisted' bathrooms with a range of adaptations for people with disabilities (e.g. 'parker' or 'arjo' baths, bath hoists etc), of which 80% had one only, 12% had two and 8% had four. Finally, 24 projects had shower rooms, of which 75% had one only, 21% had two and 4% had three.

Bedrooms

All projects provided single bedrooms. Only three projects (6%) provided double bedrooms, and in each case this was only one double bedroom in the context of the single bedroom model. Ten projects (20%) provided one or more en-suite bedrooms, of which two were entirely en-suite projects.

Public rooms

Similarly, projects provided a range of public rooms with a mix of separate rooms (e.g. sitting rooms) and combined rooms (e.g. kitchen/dining rooms). Overall, 22 projects (43%) had a total of two public rooms; 16 projects (31%) had three public rooms; eight projects (16%) had four public rooms; four projects (8%) had six public rooms (two of which were projects comprising three linked flatlets); and one project (2%) had eight public rooms (including two kitchens, two dining rooms and four living rooms of varying sizes). Forty-one projects (80%) had utility or laundry rooms; one project (2%) had a conservatory; and one project (2%) had a summerhouse.

Other/specialist rooms

Five projects (10%) had 'activity' rooms; 12 projects (24%) had 'quiet' or relaxation rooms; and more unusually in domestic scale settings, two projects (4%) had specialist 'snozelen' rooms.

Storage

Eleven projects (22%) had provided extra storage space (e.g. for specialist equipment, wheelchairs etc) as part of the preparation of the property for client use.

Safety

Ten projects (20%) had included safety features in the design or preparation of the glazed features of the accommodation e.g. toughened glass in windows; and 22 projects (43%) employed various alarm systems, including full staff call systems throughout the accommodation (18%), partial staff call systems in bathrooms (12%), intercoms (8%), and bedroom door alarms (6%).

Garden

Only one project (2%) had no garden. Five projects (10%) had shared gardens, 15 projects (29%) had regular private gardens, and 30 projects (59%) had so-called 'secure' gardens in which various measures were employed to prevent client's egress without staff knowledge.

Transport

Almost all projects (94%) made use of public transport, as well as travelling by other means. Twenty-one projects (41%) had their own dedicated transport, and a further 19 projects (37%) had access to transport shared with one or more other projects within the same organisation. Eleven projects (22%) had no transport attached to the project and no access to a shared vehicle. In addition, 21 projects (41%) allowed clients to travel in staff's own cars, but this was not permitted in respect of the remaining 30 projects (59%).

7.3 Views of Staff on Quality of Accommodation

Project managers were requested to make observations, and invited to provide opinions, on a number of aspects of the match between the type, design and quality of accommodation, and the perceived characteristics of the resident group of clients. In addition, they were asked to rate some aspects of the project on a five-point scale (*not at all, a little, moderately, mostly, completely*).

Meeting Clients' Needs

In relation to the needs of the client group, 90% of projects were rated as having accommodation that met clients' needs mostly or completely. However, as shown in Table 7.5, three projects (6%) met clients' needs only a little and two projects (4%) met clients' needs moderately.

Table 7.5: Accommodation Design - Client Needs

Design meets clients' needs?	Projects (*N* = 51)	
	N	%
Not at all	-	-
A little	3	5.9
Moderately	2	3.9
Mostly	36	70.6
Completely	10	19.6

As shown in Table 7.6, in 21 projects (41%) the best feature in terms of meeting needs was that clients had their own individual bedrooms (e.g. in terms of privacy); in 11 projects (22%), internal space was identified as the best accommodation feature, providing the greatest contribution to meeting clients' needs (e.g. large bedrooms, big kitchens); in six projects (12%) the general design and layout was reported to be the best feature in meeting clients' needs (e.g. open plan living space, accessibility for clients); and in five projects (10%), location and external space were mentioned as the best features (e.g. location near to amenities, safe environment, secure garden).

Table 7.6: Best Accommodation Feature – Client Needs

Accommodation Feature	Projects (*N* = 51)	
	N	%
Ordinary house	3	5.9
Location and external space	5	9.8
Accessibility	3	5.9
Internal space	11	21.6
Design and layout	6	11.8
Clients have own rooms	21	41.2
Other (miscellaneous)	2	3.9

However, some of the design features mentioned as important in meeting clients' needs were noted to be the worst features of some project accommodation also. As shown in Table 7.7, lack of internal space (e.g. not enough room generally, narrow corridors, small kitchens) was cited as the worst feature, which met clients' needs least, in 12 projects (24%); poor design and layout (e.g. small

windows providing poor light, lack of soundproofing, open plan kitchens with no easy way of preventing unsupervised client access) were problematic in 10 projects (20%); stairs (e.g. too steep, difficult for clients with increasing dependency or frailty) were mentioned as a specific issue in relation to the needs of clients in nine projects (18%); and poor bathrooms or inadequate bathroom equipment were mentioned in relation to six projects (12%).

Table 7.7: Worst Accommodation Feature – Client Needs

Accommodation Feature	Projects (*N* = 51)	
	N	%
None	8	15.7
Location and external space	6	11.8
Internal space	12	23.5
Design and layout	10	19.6
Stairs	9	17.6
Bathrooms and bathing equipment	6	11.8

All the projects had been set up on the basis of providing 'a home for life' for the clients (former hospital inpatients), and in the majority of properties (63%) the resident group had been stable over the duration of the project. However, staff reported that a total of 26 clients had moved on from 19 projects (37%), as a result of social, health and dependency related problems. As shown in Table 7.8, two clients (8%) made a positive transition as a result of their increasing independence; and sadly, eight clients (31%) died. However, some moves reflected a lack of match, or an increasingly poor fit, between the project accommodation and the changing needs of clients. Six clients (23%) moved because the accommodation became unsuitable as their dependency increased; a further six clients (23%) moved because their physical or mental health needs could not be met in the accommodation; and three clients (12%) moved as their behaviour problems could not be managed in the project environment.

Table 7.8: Transition of Residents

Main Reason for Transition		Clients Moved (*N* = 26)	
		N	%
Dependency	More independent	2	7.7
	More dependent	6	23.1
Social	Compatibility problem	1	3.8
	Behaviour problem	3	11.5
Health	Mental health problem	2	7.7
	Physical health problem	4	15.4
	Died	8	30.8

Physical Robustness

In relation to the physical aspects of the accommodation, all properties were rated as moderately robust or better. As shown in Table 7.9, 10 projects (20%) were reported to be moderately robust, 34 projects (67%) were rated as mostly robust, and seven projects (14%) were described as completely robust.

Table 7.9: Accommodation Robustness

Project Physically Robust?	Projects (*N* = 51)	
	N	%
Not at all	-	-
A little	-	-
Moderately	10	19.6
Mostly	34	66.7
Completely	7	13.7

However, 32 projects (63%) had required physical repairs to the fabric of the property, over and above that which could be regarded as routine maintenance. Of these, the majority of repairs were as a result of dents and holes in walls (34%), dampness or the impact of flooding (22%), broken doors (13%), and broken windows (9%).

Assisting Staff Care and Support

As a care environment, 80% of projects were rated as having design features that assisted staff in providing care and support to clients mostly or completely. However, as shown in Table 7.10, the design features of three projects (6%) did not assist staff in their care tasks at all, and in a further three projects (6%) assisted staff only a little.

Table 7.10: Accommodation Design - Care and Support

Design Assists Care?	Projects (*N* = 51)	
	N	%
Not at all	3	5.9
A little	3	5.9
Moderately	4	7.8
Mostly	32	62.7
Completely	9	17.6

As shown in Table 7.11, in 20 projects (39%) internal space (e.g. large rooms, wide corridors) was identified as the best accommodation feature, providing the

greatest assistance to staff in relation to care tasks; in seven projects (14%) the key issue for staff was the extent to which the accommodation afforded good observation and supervision of residents; in six projects (12%) the general design and layout were cited as the best features in assisting client care (e.g. open plan rooms, accommodation on one level); and in a further six projects (12%) actual staff numbers (e.g. permitting one-to-one working) and the accommodation available for staff use (e.g. availability of a separate staff office) were mentioned as supporting client care. However, in three projects (6%) it was reported that the accommodation had no features thought to assist staff in providing care and support to clients.

Table 7.11: Best Accommodation Feature – Assisting Care and Support

Accommodation Feature	Projects (*N* = 51)	
	N	%
None	3	5.9
Location	4	7.8
Internal space	20	39.2
Design and layout	6	11.8
Privacy	1	2.0
Equipment	4	7.8
Observation and supervision	7	13.7
Staffing and staff accommodation	6	11.8

Some of the same key design features were mentioned as the worst aspects of project accommodation also. As shown in Table 7.12, lack of internal space (e.g. small bathrooms) was problematic in 14 projects (28%); poor staff accommodation (e.g. combined office and staff sleepover room) was rated as the worst accommodation feature in 11 projects (22%); and lack of equipment (e.g. no hoist in bathroom, no staff call system) was reported as hindering care and support in five projects (10%). However in 14 projects (28%) staff did not identify any accommodation feature as limiting staff in carrying out their care tasks.

Table 7.12: Worst Accommodation Feature – Hindering Care and Support

Accommodation Feature	Projects (*N* = 51)	
	N	%
None	14	27.5
Location and external space	2	3.9
Internal space	14	27.5
Stairs	2	3.9
Equipment	5	9.8
Observation and supervision	3	5.9
Staffing and staff accommodation	11	21.6

Supporting Group Living

The extent to which the accommodation supported group or shared living was more variable. In 39% of projects, staff reported that clients sharing the accommodation had gelled as a group only moderately or less: in 13 projects (26%) the client mix had gelled moderately; in three projects (6%) residents had gelled only a little; and in four projects (8%) staff reported no evidence of group coalescence. However, the accommodation arrangements had promoted or supported group living mostly in 24 projects (47%), and completely in seven projects (14%).

Table 7.13: Accommodation Design – Group Living

Clients gelled?	Projects (*N* = 51)	
	N	%
Not at all	4	7.8
A little	3	5.9
Moderately	13	25.5
Mostly	24	47.1
Completely	7	13.7

In 31 projects (61%), staff suggested that the quality of life of one or more clients would be improved in alternative accommodation with fewer residents. Staff in 14 projects (28%) indicated that a smaller size group home (e.g. two or three people sharing only) would be the preferred living arrangement for their clients; but in seventeen projects (33%), staff considered the most suitable alternative for some of their residents would be an entirely different project model based on single tenancies.

Achieving Housing Integration

The type and design of the majority of project accommodation (80%) was considered by staff to integrate mostly or completely with other properties in the immediate neighbourhood. This finding was unsurprising given the high proportion of ordinary pre-existing housing (either adapted for the client group or regular housing stock) that was used for projects (55%), but suggested that much of the purpose built accommodation was of a design sympathetic to the locality also.

However, as shown in Table 7.14, three projects (6%) were considered to blend with neighbouring accommodation only moderately; a further three projects (6%) only a little; and four projects (8%) not at all. All seven projects with the poorest ratings for integration with local community accommodation were purpose built projects: three were moderate size projects (five or six places) but

of a markedly different architectural design from neighbouring properties; and four were large projects (eight or nine places) on a different scale from local housing, suggesting an 'institutional' purpose rather than regular domestic use.

Table 7.14: Accommodation Fit - Integration with Neighbourhood

Fit with neighbourhood?	Projects (*N* = 51)	
	N	%
Not at all	4	7.8
A little	3	5.9
Moderately	3	5.9
Mostly	7	13.7
Completely	34	66.7

Supporting Clients' Integration/Acceptance

The clients residing in the majority of projects (82%) were considered by staff to have been accepted mostly or completely by the local community in the neighbourhood. Staff reported some degree of social acceptance in all projects, however, as shown in Table 7.15, in nine projects (18%) clients were accepted only moderately or a little.

Table 7.15: Resident Fit – Integration with Local Community

Accepted in neighbourhood?	Projects (*N* = 51)	
	N	%
Not at all	-	-
A little	1	2.0
Moderately	8	15.7
Mostly	25	49.0
Completely	17	33.3

Staff attributed the lower levels of social acceptance to two main issues: some residents displayed behaviour problems that marked them out as different to others in these communities; and some projects were perceived to have impacted in a negative way on local neighbours. In 13 projects (26%) staff reported experience of problems with the local community at the planning or development stages (e.g. a petition to stop the project); and in eight projects (16%) there remained contemporaneous problems with neighbours (e.g. complaints about noise, complaints about rubbish/waste, complaints about the number of staff cars parked in the street) or frictions about the legitimacy of the clients' rights to live in the neighbourhood (e.g. 'they shouldn't be here').

7.4 Analysis of Psychometric Properties of the 'Housing Scale'

As noted, some items on the Housing Questionnaire were open-ended, providing opportunities for the unrestricted views of the staff respondents to be captured. However, the six key leading items (meeting client needs, physical robustness, assisting staff care, group living, achieving housing integration and supporting client acceptance) were formatted for responses on the following five-point scale:

1	2	3	4	5
Not at all	*A little*	*Moderately*	*Mostly*	*Completely*

The information collected on these items was subject to the qualitative analysis of responses described in section 7.3. However, in addition, *scores* could be assigned to the five scale points (e.g. such that '*Not at all*' achieved a score of zero, and '*Completely*' achieved a score of four) and so an initial evaluation of the psychometric properties of the resultant putative 'housing scale' was carried out to determine the potential for further quantitative analysis.

The evaluation of psychometric properties included analyses of missing values, response frequency, item correlations, reliability (internal consistency), all of which were performed at the level of the total group of respondents ($N = 51$) equating to the number of accommodation projects.

Missing Values

There were no missing values within this set of items. As the Housing Questionnaire was administered by interview, it was possible for respondents to request clarification of items (if necessary), thus increasing the likelihood of obtaining a response. In the event, the staff respondents found no difficulty with the scale items and all 51 respondents provided answers to all items. Therefore the usual procedure of replacing low rate missing values with the series mean prior to subsequent analysis of reliability and correlations was unnecessary.

Frequencies

Analyses of raw data response frequencies were carried out to examine the distribution of responses across the five point rating scale for each of the six items. Typical scale construction guidance suggests that if items have two or more adjacent scale points accounting for less than 10% of responses, this may indicate frequency problems, indicating a poor item, failing to discriminate adequately between sections of the instrument's target population. However, the response frequency distributions for the housing scale required to be approached with caution, as the distribution skew or kurtosis on some items might reflect accurately the particular accommodation within the sample of projects (i.e. as new social care homes, some of which had been purpose built or adapted for ID

clients) rather than a signal of scale problems. For example, many projects had been planned to meet the needs of specific groups of clients (item 1) and designed to be sufficiently physically robust (item 2) to provide appropriate accommodation for clients with challenging behaviours.

The response frequencies for the total respondent group are presented in Table 7.16. For this dataset, possible frequency problems were noted on items 1 (client needs), 2 (robustness) and 6 (acceptance).

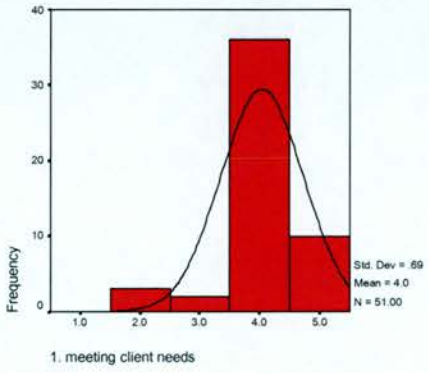
Table 7.16: Response Frequencies for Housing Scale Items (*N*=51)

Item	Project/Accommodation Facet	Response %				
		1	*2*	*3*	*4*	*5*
1	Meeting Client Needs	0	5.9	3.9	70.6	19.6
2	Physical Robustness	0	0	19.6	66.7	13.7
3	Assisting Staff Care	5.9	5.9	7.8	62.7	17.6
4	Supporting Group Living	7.8	5.9	25.5	47.1	13.7
5	Achieving Housing Integration	7.8	5.9	5.9	13.7	66.7
6	Supporting Client Acceptance	0	2.0	15.7	49.0	33.3

Red: denotes adjacent scale points with < 10% responses

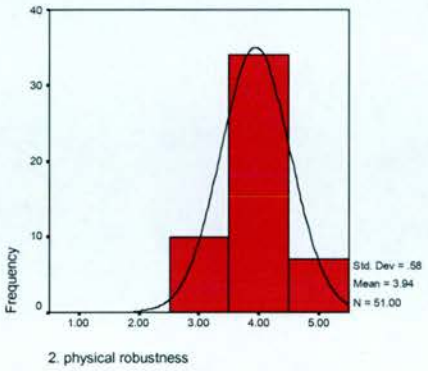
As shown in Table 7.16 and Figure 7.2, 90.2% of respondents rated their project's accommodation as meeting clients' needs at the upper scale points of 4/5 *(mostly/completely)*, compared with only 5.9% responding at scale points 1/2 *(not at all/a little)*.

Figure 7.2: Frequency Distributions for Client Needs (item 1)



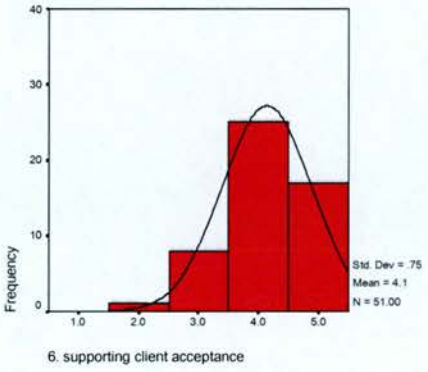
As shown in Table 7.16 and Figure 7.3, 80.4% of respondents rated the physical robustness of their project's accommodation at the upper scale points of 4/5 *(mostly/completely)*, compared with zero responses at scale points 1/2 *(not at all/a little)*.

Figure 7.3: Frequency Distributions for Physical Robustness (item 2)



Finally, as shown in Table 7.16 and Figure 7.4, 82.3% of respondents rated their project's accommodation as supporting client integration and acceptance at the upper scale points of 4/5 *(mostly/completely)*, compared with only 2.0% responses at scale points 1/2 *(not at all/a little)*.

Figure 7.4: Frequency Distributions for Client Acceptance (item 6)



However, in the context of these specific projects, the high degree of satisfaction with these aspects of the projects seemed to be an accurate reflection of the extant situation and the fact that so many projects had been custom designed or specially adapted with the needs and interests of clients in mind.

Correlations

As a first step in scale analysis, simple Pearson's Product Moment correlations were carried out to determine the extent of inter-item correlations and the loading of each of the six items on the total scale.

Exploration of the relationships between items revealed a pattern of relatively weak associations. As shown in Table 7.17, there were two significant positive inter-item correlations only: the items on meeting client needs and assisting staff care were highly correlated (r=0.7); and the items on client acceptance and physical robustness were more moderately correlated (r=0.3).

Table 7.17: Housing Scale Inter-Item Correlation Matrix (N = 51)

Item	Project/Accommodation Facet	Needs	Robust	Care	Group	Integrate	Accept
1	Meeting Client Needs	1.00					
2	Physical Robustness	0.06	1.00				
3	Assisting Staff Care	0.65**	0.08	1.00			
4	Supporting Group Living	0.08	0.02	0.27	1.00		
5	Achieving Housing Integration	0.15	-0.03	0.21	0.10	1.00	
6	Supporting Client Acceptance	0.14	0.34*	0.22	0.01	0.19	1.00

** Significant at 0.1 level (2-tailed) * Significant at 0.5 level (2-tailed)

The strong relationship between 'meeting client needs' and 'assisting staff care' would be predicted for projects where the accommodation was designed for the specific group of occupants, and suggested that the housing design was appropriately geared to both the needs of residents and the requirements of staff in carrying out care tasks to meet those needs. The relationship between 'physical robustness' and 'client acceptance' was more unexpected, but may be accounted for by the levels of challenging behaviours exhibited by clients in projects where physically robust design features were required (e.g. toughened glass in windows where client breakage rates were high, avoidance of plasterboard where clients were prone to kick or head bang walls). On this basis, projects with high robustness ratings might be associated with lower levels of client acceptance linked to low tolerance of such (undesirable) behaviours in the local community.

Further examination of the loading of each item on the total scale indicated that all items showed significant positive correlations with the total scale score.

Table 7.18: Housing Scale Item-Total Correlations (N = 51)

Item	Project/Accommodation Facet	Item-Total Correlations
1	Meeting Client Needs	0.58**
2	Physical Robustness	0.31*
3	Assisting Staff Care	0.74**
4	Supporting Group Living	0.51**
5	Achieving Housing Integration	0.61**
6	Supporting Client Acceptance	0.51**

** Significant at 0.1 level (2-tailed) * Significant at 0.5 level (2-tailed)

As shown in Table 7.18, three items (needs, care, integration) showed high correlations (r>0.6); two items (group, acceptance) showed moderate correlations (r=0.5); but one item (physical robustness) demonstrated a relatively poorer correlation than all the other items (r=0.3), suggesting that this item had a weaker association with the item set than other items.

With due regard for caution in relation to the relatively small dataset, the overall pattern of inter-item correlations suggested that the scale items were measuring a range of different aspects of the impact of the accommodation, and thus might contribute conceptually to a more global measure of housing quality or fit; and the item-total correlations suggested that (with the one possible exception of item 2 (physical robustness) the items seemed to have potential as a summated housing scale, therefore further analysis of scale reliability was carried out.

Reliability

The reliability of the housing scale was examined using Cronbach alpha. This measure of reliability examined the internal consistency among the items within the summated scale. Alpha values of 0.7 or higher are regarded as indicating an acceptable level of internal consistency; and alpha values of 0.6 or higher are considered satisfactory within the context of exploratory studies (Hair et al, 1998). As part of the reliability analysis, corrected item-total correlations (the correlation of each item to the summated scale score calculated *without* the contribution of that item) were scrutinised also. A scale with good internal consistency might be expected to demonstrate item-total correlations of 0.4 or above. For the purposes of exploratory work, an acceptable threshold level of internal consistency might be set at 0.3; and item-total correlations below the threshold of 0.25 might be indicative of possible problems with an item (Kline, 1993).

A summary of the housing scale reliability analysis, showing Alpha values and corrected item-total correlations is presented in Table 7.19.

Table 7.19: Reliability Indices for Housing Scale Variations (N = 51)

Item	Project/Accommodation Facet	Corrected Item-Total Correlations		
	No of items	*6*	*5*	*4*
1	Meeting Client Needs	0.40	0.40	0.45
2	Physical Robustness	0.12	-	-
3	Assisting Staff Care	0.51	0.52	0.48
4	Supporting Group Living	0.18	0.19	-
5	Achieving Housing Integration	0.22	0.25	0.25
6	Supporting Client Acceptance	0.29	0.22	0.26
	Cronbach Alpha	0.521	0.530	0.546

Given the small size of the accommodation survey, with only 51 participating projects, it was not expected that threshold levels of internal consistency would be met in all cases. However, Cronbach alpha values for the scale approached an acceptable level from 0.52 to 0.55 depending on the set of items included (suggesting that an acceptable level of alpha might be demonstrated with a larger sample).

For the full set of six items, corrected item-total correlations reached 0.4 or higher on two items and 0.3 or higher (rounded values) on three items. If item 2 (physical robustness), which had the lowest corrected item-total correlation, was dropped from the scale to make a set of five items, corrected item-total correlations reached 0.4 or higher on two items and 0.3 or higher (rounded values) on three items. Finally, if item 4 (supporting group living), which had the next lowest corrected item-total correlation, was dropped from the scale to make a set of four items only, corrected item-total correlations reached 0.4 or higher on two items and 0.3 or higher (rounded values) all four items.

The very low corrected item-total correlation ($r = 0.1$) demonstrated for item 2 (physical robustness) flagged this immediately as a problem item with poor internal consistency. It may be that this item reflects a different housing dimension (e.g. basic construction) that cannot be treated in an additive manner with the other more client orientated accommodation features to form a housing scale. The relatively low corrected item-total correlation demonstrated for item 4 (supporting group living) may also reflect poor fit with the putative scale, but the slight increase in value ($r = 0.2$) in the five-item scale suggested that this might be worth retaining for further evaluation of internal consistency with the larger sample.

The impact of the remaining four items on the relevant scale alpha value was examined also. This indicated that for three items (1, 3 and 6) alpha would decrease if the items were deleted; but suggested if item 5 (housing integration) were dropped in a further reliability run, alpha would increase to 0.6. However, further item deletion would have reduced the scale to three items, and as four item scores would generally be regarded as the minimum required for assessing the internal consistency of a scale (Kline, 1983), the reliability analysis would have become less robust.

Overall, given the small size of the dataset (and the fact that this was a post hoc analysis of an embryonic scale, the content of which was set by a supporting agency's interests, rather than by a set of empirically driven research questions), the housing scale was found to have a reasonable level of internal consistency in relation to the five-item format. Therefore, the total scores from this five-item version of the instrument were calculated and used to explore possible differences in housing quality in relation to the fit between the residents and the characteristics of the accommodation.

7.5 Housing Fit Index

Scores were assigned to the items in the housing scale, and the sum of the scores across the five items was calculated and transformed to form a 'housing fit index' (HFI) reflecting the degree of fit between the resident clients (with their varying care needs) and the particular characteristics and style of the project accommodation. A summary of the HFI statistics is presented in Table 7.20.

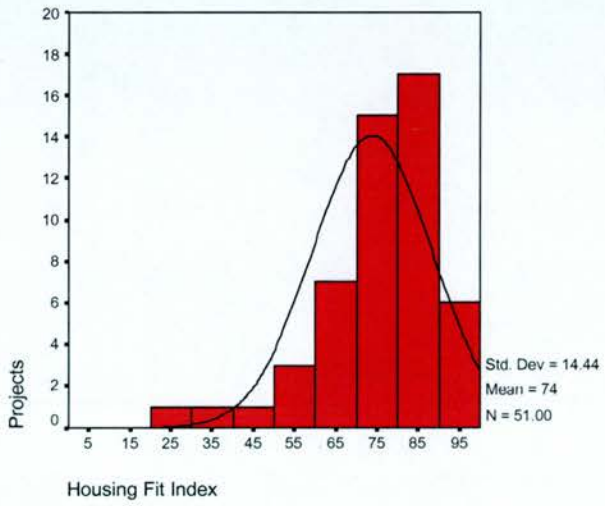
Table 7.20: Summary Statistics - Housing Fit Index (HFI)

Accommodation	*N*	Min Score	Max Score	Mean	*SD*	Range	Extremes
All Projects	51	0	100	73.8	± 14.44	25-95	2 (<35)

The assignment of scores was such that '*Not at all*' scored zero, '*A little*' scored one; '*Moderately*' scored two; '*Mostly*' scored three; and '*Completely*' scored four. This provided a scale with potential total raw scores from 0-20 for the five items. For ease of use (to promote intelligibility) the total raw score was transformed (multiplied by five) to form a scale with a minimum score of 0 and a maximum score of 100.

The HFI scores achieved by the 51 projects in the community accommodation survey are shown in Figure 7.5.

Figure 7.5: Frequency Distributions of Project Housing Fit Indices



As shown in Figure 7.5 and Table 7.20, overall the community accommodation projects scored well on the HFI, with a mean score of 74 and a standard deviation of 14.

At the high end of the distribution, there were six projects with scores higher than one standard deviation above the mean, all of which were examples of small to moderate size projects (3-6 places), four of which achieved HFIs of 90 and two of which achieved HFIs of 95. However, there were three projects with scores lower than *two* standard deviations below the mean. Two of these projects were outliers, at the extreme of the range of scores. These were examples of the largest and the smallest community projects (8 and 3 places), and achieved HFIs of only 25 and 35 respectively. The third project was another example of a large project (9 places) and achieved an HFI of 45.

The three projects with HFIs at the low extreme of scores appeared to reflect a poor fit between the residents and the characteristics of the project accommodation. In all three cases, in tandem with responses to the housing scale items, staff respondents provided informal and unprompted reports of dissatisfaction with the circumstances of the project (e.g. location, design, resident mix) also.

Following the study it was learned that the organisations providing two of these projects had entered into discussions with their purchasers about the further relocation of the residents to alternative accommodation, and subsequently the projects closed. These two projects had been open for longer than the third low scoring project, and therefore various shortfalls in effectiveness may have been recognised by the providers over time. This outcome was unforeseen, but seemed to provide some validation of the HFI as an instrument with the potential to discriminate between projects with a poor match between clients and their accommodation.

The next step in scale analysis was to explore the HFIs of projects grouped according to ten of the main features identified in the current (limited) accommodation survey, to determine whether any specific variables seemed to be associated with lower scoring projects.

A series of comparisons were made between the HFIs of projects in relation to: geographical area and location; accommodation design, type and size (number of places); project duration; resident stability; and the presence or absence of local community or neighbourhood problems. Although it was anticipated that some project variables would have little or no impact on overall housing fit (e.g. geographical area), it was thought that others (e.g. project size) might be associated with differences in HFIs.

A one-way of analysis of variance of project HFIs carried out in relation to the first five project variables revealed no significant differences. As shown in Table 7.21, similar HFIs were found irrespective of the area in which projects were sited, the accommodation design and type (flat, house etc), the number of residential places, and the overall duration of the project.

Table 7.21: Analysis of Housing Fit Index Scores by Project Characteristics (1-5)

Project / Accommodation	Categories	*N*	HFI Mean	*SD*	Range	One-Way ANOVAs *df*	*F*	*p* <
Area	City	20	69.0	± 17.37	25-95	*F* 2, 48	2.274	NS
	West	12	79.6	± 8.12	60-90			
	South	19	75.3	± 13.07	55-95			
Design	Purpose built	23	72.8	± 16.08	25-95	*F* 2, 48	0.458	NS
	Adapted	18	76.4	± 10.68	60-95			
	Regular stock	10	71.5	± 17.01	35-90			
Type (1) *	Flat	8	73.1	± 18.11	35-90	*F* 3, 46	0.149	NS
	Bungalow	19	73.2	± 16.26	25-95			
	Semi/Terraced	13	75.8	± 9.97	60-95			
	Detached house	10	76.0	± 11.74	55-90			
Size	3-4 places	18	73.9	± 14.51	35-95	*F* 2, 48	1.381	NS
	5-6 places	23	76.5	± 11.33	55-95			
	7+ places	10	67.5	± 19.61	25-85			
Project Duration	1-2 years	13	70.0	± 18.26	25-95	*F* 2, 48	0.640	NS
	3-4 years	21	75.7	± 12.58	45-95			
	5+ years	17	74.4	± 13.68	35-90			

* Missing case = 1 (Residential care home not included in this analysis)

With one exception, a series of t-tests revealed a similar pattern of no significant differences between total housing scores as measured by the HFI in relation to a further five project variables.

Table 7.22: Analysis of Housing Fit Index Scores by Project Characteristics (6-10)

Project / Accommodation	Categories	*N*	HFI Mean	*SD*	Range	2-tailed t tests *t*	*df*	*p* <
Location	Urban/suburban	45	72.8	± 14.87	25-95	-1.431	49	NS
	Rural/semi rural	6	81.7	± 7.53	75.90			
Type (2)	Physically linked (e.g. flats)	22	73.4	± 14.42	35-95	-0.177	49	NS
	Physically separate	29	74.1	± 14.70	25-95			
Resident Stability	Clients Moved	19	70.8	± 15.92	35-95	-1.160	49	NS
	Clients Not Moved	32	75.6	± 13.43	25-95			
Local Community Problems (1)	Initial Problems	13	68.1	± 17.02	25-90	-1.693	49	NS
	No Initial Problems	38	75.8	± 13.13	35-95			
Local Community Problems (2)	Current Problems	8	61.9	± 18.11	25-85	-2.705	49	0.01
	No Current Problems	43	76.1	± 12.70	35-95			

As shown in Table 7.22, the urban or rural location of projects, whether the accommodation was physically linked to other housing or had a degree of physical separation, the stability of the resident group, and the presence of initial problems with local neighbours had no significant effect on outcomes as measured by the HFI. However, one significant difference in HFI was found in relation to those projects experiencing contemporaneous problems with the local community or their immediate neighbours.

Considerable caution is required in relation to these findings. The project sample was small ($N = 51$), potentially atypical, and possibly more homogeneous than in other settings. For example, all but one of the care and accommodation projects had all been set up under the aegis of a recent well funded hospital resettlement programme; all the accommodation was relatively small (mean 5 places); many projects had provided opportunities for staff to relocate from the closing hospitals together with their clients; and a quarter of projects could be construed as still subject to a 'honeymoon' effect, having been open for two years or less. Similarly, the range of project characteristics available for significance testing against HFIs was limited by the study scope and objectives.

However, with these caveats, the HFIs established for this set of community accommodation seemed to reflect the (mainly) positive profiles of these specific projects; but the degree of overall fit between the clients and their accommodation did not appear to have simple associations with factors such as project location or size, accommodation type or design, the duration of projects or the stability of the client group. In the context of this dataset, it appeared that the aggregate HFIs could distinguish between projects and identify (to some extent) 'projects with problems'. However, the proposed HFI had very limited psychometric testing in this small study, and would require development, refinement and more extensive evaluation with a larger sample of projects before conclusions could be drawn reliably.

7.6 Summary and Conclusions

The projects involved in the survey of community accommodation for adults with intellectual disabilities demonstrated a range of varied characteristics. The majority of project accommodation comprised a mixture of flats, semi-detached houses, detached houses and bungalows, but there were also examples of the use of a farmhouse, a cottage and a self-contained wing of a residential care home. Approximately 80% of projects had been purpose built or specially adapted to meet the needs of the resident client group; and approximately 60% were located in ground floor dwellings. Compared with the typical size of living arrangements in the learning disabilities hospitals from which clients had relocated, all the community projects were relatively small at nine places or fewer, with around one third of projects having three or four places only, just under a half of projects having five or six places, and one fifth having between seven and nine places.

The customisation of the accommodation to meet clients' needs was reflected in the design of many projects, and examples of a variety of specialist features (e.g. barrier-free rooms, variable height kitchen surfaces, toughened glazing) and equipment (e.g. specialist baths, fixed or portable hoists, alarm or call systems) were found.

In the view of the staff with day-to-day responsibility for the projects, the majority of the accommodation met clients' needs and had features that assisted staff in carrying out care and support tasks. However, one or more clients had moved on from just over one third of projects, and 60% of these moves were occasioned by the lack of capacity of these projects to respond to the changing needs of clients. In addition, staff reported that the quality of life of one or more existing residents in 60% of projects could be improved by a move to an alternative (smaller) setting.

The majority of the accommodation was considered by staff to blend in with neighbouring properties; and the local community were thought to have accepted the resident clients relatively well in most cases.

The Housing Fit Index developed within the study, and reflecting the overall fit between the clients and the accommodation, confirmed the positive profile of the majority of projects. Overall, the total project group demonstrated a relatively high mean HFI score of 74%. At the upper end of the distribution, 12% of projects scored higher than one standard deviation above the mean. However, 16% of projects scored lower than one standard deviation below the mean, and a further 6% scored lower than two standard deviations below the mean.

A number of the project and accommodation variables measured as part of the survey were examined in relation to the HFI, but only one (contemporaneous problems with the local community or immediate neighbours) was found to have a significant impact on this embryonic measure of housing quality. However, it is possible that other more client-orientated variables (e.g. dependency) might be associated with differences in HFI also, but these were outside the scope of this part of the overall research design.

In the context of the resettlement of adults with intellectual disabilities from hospital to community care, it is difficult to determine the appropriate demarcation between the overall success or failure of projects, and even more difficult to quantify the contribution made by accommodation to this outcome. However, if the criterion of success were set at an HFI of 65% or higher, then 78% of the projects surveyed in this study could be construed as having made the grade. Of the remaining 'underachieving' projects, 18% continued to provide care and support to clients in these settings, and only 4% had relocated to alternative accommodation.

Chapter 8

Main Study: Assessment of Individuals' Quality of Life

The main study involved the use of the final version of the WHOQOL-ID (and other associated measures) to assess the quality of life of individuals in three groups: adults with intellectual disabilities in receipt of NHS care and residing in traditional types of wards in a learning disabilities hospital; adults with intellectual disabilities in receipt of social care and residing in a range of ordinary accommodation in community settings; and adult members of the general public living in similar types of housing in similar local neighbourhoods.

8.1 Introduction to Design and Methodology

The background to the design and methodology of the main study was described in Chapter 4.

The study had two foci of interest that underpinned the design issues: firstly, research questions related to possible differences in the quality of life of the three participant groups; and secondly, research objectives linked to the psychometric development of the new quality of life measure.

Therefore, the context of the study was a further field trial of the WHOQOL-ID (building on the work carried out in pilot study two) with groups of ID clients representative of the target population for the instrument in both hospital and community settings; and an associated trial of the new instrument compared with the original measure (WHOQOL-BREF[1]) in relation to a split-half group of the general population.

The principal aims of the main study were to:

1 Compare the quality of life of the two groups of adults with intellectual disabilities (matched for age, gender and dependency) and explore the degree of satisfaction reported in relation to the lifestyles and experiences associated with the two forms of supported living; and

2 Compare the quality of life of the 'cared for' adults with intellectual disabilities in hospital and community settings with that of non-intellectually disabled adults living independently (matched with both ID groups for age and gender, and matched with the community clients for locality).

[1] Augmented by the specialist ID module of nine additional facets for the purposes of comparison

The subsidiary aim was to:

3 Evaluate the psychometric properties of the WHOQOL-ID in relation to this total dataset.

8.2 Participants and Research Group Match

There were 625 participants in the study, all adults aged 18 years or over. The index cohort within the study was a group of 204 adults with intellectual disabilities in community settings; consequently, aspects of their characteristics drove the selection, recruitment and matching of the comparator hospital residents and general public participants.

Participant Types, Settings and Models of Care

Participants were recruited into three research groups: ID clients in NHS care (hospital residents), ID clients in social care (community clients) and members of the general population (general public) in approximately equal numbers. The distribution of participants by type and model of care is shown in Table 8.1.

Table 8.1: Participants by Type and Model of Care

Group	Participant Type	Model of Care	No. of Providers	*N*	%
1	Hospital residents	Healthcare	1	213	34.1
2	Community clients	Social care	12	204	32.6
3	General public	N / A	-	208	33.3
	Total			625	100.0

Community Group

Twelve different organisations were responsible for providing the care and accommodation for the community clients, and the distribution of these participants between social care providers is presented in Table 8.2. At the time of the study, the participants in the community group resided in these social care settings in the context of the 51 community accommodation projects described in Chapter 7 (in relation to the housing survey which formed the subsidiary study). All had been former residents of the large learning disabilities hospital (Hospital A), or the smaller associated hospital (Hospital B) as outlined in Chapter 4. Overall, 62% of the community residential places were provided by a voluntary agency or a housing association; a private sector provider operated 19% of the places, and a further 19% were provided by a religious order.

Table 8.2: Community Clients by Social Care Provider

Provider	Community Group Participants (*N*=204)	
	N	%
1	15	7.4
2	8	3.9
3	39	19.1
4	21	10.3
5	9	4.4
6	10	4.9
7	9	4.4
8	9	4.4
9	21	10.3
10	6	2.9
11	18	8.8
12	39	19.1

Hospital Group

The hospital group were residents of another large learning disabilities hospital (Hospital C); and therefore only one provider NHS Trust was responsible for the care and accommodation of this group of participants.

Hospital C was conceived initially as an educational and training establishment for 'imbecile'[2] children providing dormitories, classrooms and related facilities. It was established as a charitable institution with just one classroom in the early 1860s, but within a decade had expanded to accommodate approximately 100 pupils (Hutton, 2000). Although the facility started as a boarding school that 'discharged' pupils routinely at the age of eighteen, the Mental Deficiency and Lunacy (Scotland) Act 1913 provided the opportunity for the institution to be transformed into a segregated 'colony' providing lifelong care for both children and adults, regulated by the General Board of Control[3]. Subsequently, the institution became a 'special hospital' as part of the development of the National Health Service in 1948, and the bed complement was increased to provide for over 1,300 patients at the peak of development.

However, in common with Hospital A, a combination of changes in admission practice and successive small-scale resettlement initiatives slowly reduced bed numbers. When the hospital was selected as a research site there were approximately 300 in-patients remaining in Hospital C and local planning partners were at the very early stages of implementing a further resettlement programme for these residents.

[2] Contemporaneous terminology covering a range of moderate to severe intellectual disabilities
[3] Successor to the Board of Lunacy and forerunner of the Mental Welfare Commission

The circumstances of imminent change, the context of gradually reducing staff and patient numbers, and the environment of a hospital on a closure trajectory approximated closely to the situation of the community cohort prior to their transfer to social care. These similarities were such that the residents of Hospital C could be seen as pragmatic proxies for the community group during the latter stages of their residence in Hospital A, and with adequate matching on the variables of age, gender and level of dependency could be seen as 'pre-discharge' counterparts to the 'post-discharge' community clients.

General Public Group

The public participants were members of the general population living in the same range of local communities as the index community cohort. These neighbourhoods were located in a combination of urban, suburban and rural settings, and were broadly representative of the variety of communities within three local authority areas in the study region. These participants functioned as a normative comparison group within the study, which was matched with the other two groups on the variables of age and gender, and with the index community cohort on the variable of residential locality as defined by postcode district boundaries.

Recruitment and Consent

Initial discussions about the purpose of the study, its aims and possible outcomes, were held (at Director/Chief Officer level) with relevant staff in the NHS, the local authorities, and service provider organisations in the voluntary and independent sectors. Within the framework of these discussions, agency support for the project was sought; access to research sites and the pool of potential research participants was negotiated; methods of recruitment were outlined; and the arrangements underpinning consent for participation were agreed.

Participants were recruited into the main study by a combination of methods: introductory letters, initial meetings with senior care staff, and small introductory meetings with clients and/or proxy staff.

All potential participants were provided with standardised information about the research (including information on confidentiality, participant anonymity and the possibility of refusal) and given *at least 24 hours*, but usually much longer, to consider whether or not they wished to take part. Opportunities were provided for individuals to obtain further information about the project, discuss the implications of taking part, or ask questions about the process of participation. All those who did agree to participate were requested to sign an appropriate consent form.

Hospital Group - healthcare clients

The hospital group of participants were included by agreement with the hospital managers, with patients being approached initially via the clinical teams responsible for their care and treatment.

Management and clinical support, and related permissions to approach patients as potential participants, were sought at a number of levels[4]. Firstly, a meeting was held with the Chief Executive of the NHS Trust that managed Hospital C, at which general access to the hospital and to its staff and patients was negotiated for the purposes of the research project. Subsequently, as the hospital was about to undergo significant changes in relation to the planning and implementation of patient resettlement, a presentation was made to the 'Project Reference Group' responsible for the oversight of the resettlement programme. This provided the opportunity to gain joint agency support for the research, as well as to offer re-assurances that the research could be carried out in this context, without disrupting other necessary activity. Then a further presentation was made to the hospital's clinical managers during which the project, its purpose, and related procedures were described in detail. This provided the opportunity to gain multi-disciplinary support for the research from the on-site managers responsible for the day-to-day care of patients and the deployment of staff.

Following this, a meeting was held with the Consultant in Administrative Charge of the hospital (representing a temporarily depleted medical team), and it was agreed that preliminary screening information on dependency could be collected on all patients using the Wessex Schedule (Kushlick et al, 1973), a survey measure completed by staff. Thereafter, a letter of introduction (A8.1 in Appendix A) was sent to members of all the clinical teams (including medical, nursing and therapy staff) providing basic information about the project and the procedures involved.

At this early stage, it was intended that a group matching procedure would be undertaken to refine the pool of potential participants for the main part of the study. However, as the number of hospital residents declined through resettlement and the size of the index community cohort increased (as outlined in Chapter 4) this was no longer feasible and a more inclusive approach was required. To facilitate this, a meeting was arranged with the Trust's Medical Director (in the absence of substantive Consultant grade medical staff attached to the hospital at that point) to discuss which patients might be approached to take part in the study, and to agree the procedures that would be adopted to obtain appropriate consent for participation.

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[4] These initial procedures were lengthy and multi-tiered, but within the framework of major change in the hospital, staff concern for their patients and uncertainty about their own futures, and residents moving from one clinical area to another as case mix changed (and ultimately wards closed), timely and frequent communication was an important element in engaging and maintaining support.

As a result of this, no individual patients, or groups of patients, were excluded from consideration on medical grounds and thus the pool of potential participants was defined as the current in-patient group. In addition, it was agreed that where a patient lacked the capacity to give appropriate consent for participation, this might be sought from their key worker (the member of nursing staff who knew that person best) acting as their proxy.

A second letter (A8.2 in Appendix 8) was sent to clinical teams signposting the next stages of the study, during which information about patients' capacity would be collected and participant recruitment procedures would commence. A third letter (A8.3 in Appendix 8) was sent to clinical teams jointly from the principal researcher and the hospital resettlement co-ordinator (the designated contact person for the research team) providing more detailed information immediately prior to work beginning on these stages of the study; and at the same time, a letter (A8.4 in Appendix 8) summarising the agreement reached with the Medical Director and enclosing the *Research Project Summary for Doctors* (8.5 in Appendix 8) was sent to the (then) acting consultant and junior medical staff prior to patients being approached. Finally, a letter (A8.6 in Appendix 8) was sent to all the care leaders and key workers for the hospital residents inviting them to take part in the study.

Meetings were then held with these care leaders (the nurse in charge of each ward) and residents' key workers, during which the purpose of the study was explained; the basic methodology was described; the participant information and consent procedures were outlined; and preliminary guidance was sought about the capacity of each potential subject to participate directly in the study, in relation to both the consent and assessment procedures. For the purpose of the study it was agreed that if the capacity of an individual patient were unclear, it would be assumed that the person could participate directly, unless subsequently this was shown not to be practicable. This avoided the possibility of staff ruling out any patient erroneously, and ensured that the number of hospital residents contributing directly to the quality of life assessment, at least to some extent, was maximised.

Following this, small group meetings were held with those patients considered to have the capacity to understand the study purpose and procedure, to make an informed decision about taking part, and to participate directly. Those individuals identified as potentially more comfortable with a known member of staff present during the assessment, or requiring staff support to respond meaningfully (e.g. to aid communication) were included in these meetings also. A full description of the project was given and patients were encouraged to ask questions or raise concerns. The participant information sheet (A8.10 in Appendix 8) and patient consent form (A8.14 in Appendix 8) were explained in detail and, where necessary, the documents were read out and explained section at a time, in language tailored to the match the residents' level of understanding.

It was stressed that each individual could make up their own mind about whether to take part in the study, and that no unfavourable consequences would ensue from a decision not to participate. The patients were informed that their key worker had copies of these documents, so that if they had questions or concerns after the meeting, they could approach this member of staff for further discussion or clarification. Subsequently, care leaders were contacted in person or by telephone to establish if any of their patients had proceeded to give formal consent for participation in the study.

For each hospital resident considered to lack the capacity to understand the study purpose and procedure, to give consent and thus to participate directly, an appropriate proxy member of staff (the key worker, or the person considered to know the client best) was identified by the care leader. Similar small group or individual meetings (as dictated by workload and staff rosters) were held with these proxy staff, providing exactly the same information as delivered in the meetings directly with patients (as outlined above). The content and purpose of the staff participant information sheet (A8.12 in Appendix 8) and the staff consent form (A8.16 in Appendix 8) were explained and discussed, and the proxy staff were invited to participate in the study on behalf of their patients. Subsequently, follow-up contact was made with these staff to establish their decision about participation in the study.

As shown in Table 8.3, there were 280 hospital residents in the participant pool at the start of the study. Six individuals (2%) died and a further 58 (21%) were discharged in the first wave of resettlement before they could be approached as potential participants, or before assessments could be completed.

Table 8.3: Hospital Group Recruitment and Exclusions

Gender	Participant Pool	Deaths		Discharges		Non-Consent		Total Exclusions		Completed Assessments	
		N	%	*N*	%	*N*	%	*N*	%	*N*	%
Male	163	3	1.8	29	17.8	0	0	32	19.6	131	80.4
Female	117	3	2.6	29	24.8	3	2.6	35	29.9	82	70.1
Total	280	6	2.1	58	20.7	3	1.1	67	23.9	213	76.1

Of the *total participant pool*, 213 hospital residents (76%) participated in the study (representing 99% of the 216 individuals in the *available participant pool*), and three female patients (1%) were excluded from the study following their informed refusal to participate[5].

[5] No proxy staff declined to participate on behalf of a patient

Community Group - social care clients

The community group of participants were included by agreement with the senior managers of the social care organisations, with clients being approached initially via the staff teams responsible for their care and support.

As with the hospital group, management support and related permissions to approach clients as potential participants was required at a number of levels. Initial meetings were held with the Directors/Heads of Social Work of the three local authorities that were *purchasers* of the social care, at which support for the research and general access to clients was sought. By agreement, an introductory letter (A8.7 in Appendix 8) was prepared for these three individuals to send directly to their counterparts in the 12 agencies that were *providers* of the social care, in which the support of these provider organisations was invited, and the co-operation of social care staff in the 51 community projects was requested. This letter was followed up by a second letter (A8.8 in Appendix 8) from the principal researcher to the Directors of these provider organisations, in which an opportunity for a meeting to discuss the research, its purpose and related procedures was sought. The response from the Directors of the provider organisations was uniformly positive, and at the subsequent meetings the support of all the social care providers was engaged, their agreement to cascade relevant information about the research within their organisations was obtained, and contact information for each social care project was made available.

Each community project was approached via an introductory letter (see example at A8.9 in Appendix 8) to the project manager/leader, a few weeks prior to the inclusion of that project in the work schedule. Meetings were then held with the project leaders and clients' key workers, during which the purpose of the study was explained; the basic methodology was described; the participant information and consent procedures were outlined; and preliminary guidance was sought about the capacity of each potential subject to participate directly in the study, in relation to both the consent and assessment procedures.

Finally, small group meetings were held with both clients and designated key staff, and exactly the same recruitment and consent procedures as described for the hospital group participants were followed, using the community versions of the participant information sheets (A8.11 and A8.13 in Appendix 8) and participant consent forms (A8.15 and A8.17 in Appendix 8).

There were 219 community clients in the participant pool at the start of the study: the original group of 180 clients who were formerly residents of Hospital A, plus an additional group of 39 clients who were former residents of the smaller Hospital B, all of whom had transferred to community care between 1994 and 1999. As shown in Table 8.4, three individuals (1%) died and a further 10 (5%) moved to alternative forms of care before they could be approached as potential participants.

Table 8.4: Community Group Recruitment and Exclusions

Gender	Participant Pool	Deaths		Moves to Alternative Care		Non-Consent		Total Exclusions		Completed Assessments	
		N	%	*N*	%	*N*	%	*N*	%	*N*	%
Male	135	2	1.5	7	5.2	0	0	9	6.7	126	93.3
Female	84	1	1.2	3	3.6	2	2.4	6	7.1	78	92.9
Total	219	3	1.4	10	4.6	2	0.9	15	6.8	204	93.2

Of the *total participant pool*, 204 community clients (93%) participated in the study (representing 99% of the 206 individuals in the *available participant pool*), and two female clients (1%) were excluded from the study following their informed refusal to participate[6].

General Public Group

A number of ways of approaching the general public as potential participants were considered, but the requirement to achieve an adequate match with the index community cohort (on age, gender and residential locality) rendered many traditional general population recruitment methods impractical. For example, initial contact by telephone (dialling within relevant subscriber codes) or letter (using the local electoral register as an address source) could have provided a starting point for a locality match, but would have required a very large group of people to be approached in order to achieve the required age and gender structure within the respondent group, and would have been subject to bias in relation to the lack of completeness of these listings. Advertising (e.g. via local radio or newspapers) for participants meeting the criteria for the matching variables could have overcome some of the contact wastage problems, but might have been prone to bias also in relation to the sectors of the population likely to receive, and respond, to such an advertisement.

The Community Health Index (CHI) provided a more comprehensive sampling frame that included the relevant characteristics of the local general population. Since the early 1990s, all persons registered with a general practitioner in Scotland (and all those having other contact with NHS Scotland organisations e.g. child or adult health screening systems) have been assigned a CHI number on one of eight discrete CHI databases linked to designated geographical areas. The CHI number[7] is a unique ten-digit identifier that includes the date of birth (first six numbers) and gender of the individual; and the CHI core dataset includes, inter-alia, name, address, postcode, area of residence, name of general practitioner and GP practice code.

[6] No proxy staff declined to participate on behalf of a community client

[7] The CHI number was under review in 2001/2002 and may be amended to provide a system of distinguishing, but non patient-identifiable, numbers in line with the requirements of the Data Protection Act (1998) and the Caldicott Guidelines (1997, 1999)

Data ownership of the CHI resides with the Chief Medical Officer (on behalf of Scottish Ministers), but in practice the Director of Public Health in each health authority is the 'data holder' who makes decisions on access to the index and the uses that may be made of the data held on the CHI. With appropriate permissions and safeguards, the CHI may be used as a sampling frame for health and healthcare needs surveys, or for other population based research. However, despite its relative comprehensiveness, caution needs to be exercised in regard to the CHI, as some individuals within a given locality may not be represented if they are not registered with a GP or in contact with other relevant health programmes (e.g. those recently arrived in an area) and others may be falsely represented (e.g. as a result of failure to notify a change of address, or a death). Therefore some bias may attach to any sample drawn from the CHI; and some survey non-responses (e.g. post office returns of survey packages) may be related to the extent of recent system updating.

A meeting was arranged with the Chief Executive of the health authority, at which general support for the research and for access to the CHI was sought and obtained. Subsequently, appropriate information was sent to the Director of Public Health and a meeting was held to discuss the framework within which access could be granted. In view of the confidentiality issues attaching to the CHI, its use as a sampling frame for research purposes is usually approved on the basis of 'blind access' only, i.e. the researcher does not have direct access to the database, but CHI staff create appropriate pools of potential general public participants for studies, according to agreed sampling parameters (in the present study, stratified quota sampling), and organise the distribution of relevant research materials (invitations to participate in research, study materials etc.) to the individuals so identified.

The general public participants were approached via a letter from the Director of Public Health (A8.29 in Appendix 8) within the context of a study information pack in which the background to this 'blind contact' was explained, and the invitation to participate in the study was extended on behalf of the principal researcher. The DPH letter made clear that no one was obliged to take part and stressed that individuals who refused would not receive further unwelcome contact. A letter from the principal researcher (A8.30 in Appendix 8) was included in the pack also. This letter provided information about the study; outlined what participation would entail; referred potential participants to the more detailed participant information sheet (A8.31 in Appendix 8); reiterated the voluntary nature of participation; and made reference to the relevant non-consent form (A8.32 and A8.33 in Appendix 8) on which refusal could be signalled. Thus the method of recruitment of general public participants provided clear routes for those approached to actively 'opt-in' (complete and return the questionnaire); actively 'opt-out' (return the refusal form); or passively 'opt-out' by doing nothing. The identity of those approached to participate was unknown to the researcher, and therefore anonymity was safeguarded unless individuals chose to reveal their identity through one of the active response choices.

The stratified quota sampling parameters for recruitment of the general public group were underpinned by the distribution of the index community clients by age, gender and locality. There were 204 such community clients (126 males and 78 females), aged between 27 and 86 years, residing in 25 local postcode districts. The distribution of the community cohort on these variables is shown in Table 8.5, with the age of these clients aggregated into ten-year bandings for ease of sampling.

Table 8.5: Distribution of Community Cohort by Age, Gender and Postcode District

Postcode District	Age Bands (years)															
	20-29		30-39		40-49		50-59		60-69		70-79		80-89		Total	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F
4							1		4						5	0
6			3			1		6				1			3	8
7									1	3	3			2	4	5
8					1			4	1	1					2	5
9										1					0	1
10	1		1	1	1	1									3	2
11			3		1		7								11	0
12			1		1			1							2	1
14			2		4		1								7	0
15					5	3	6	1		2					11	6
16							1			1		1	2		3	2
17					1	6		1							1	7
19			1	2	1			1			1				3	3
22			4	6	4	1	5	2	2	2	4				19	11
23					2		1		1						4	0
24		2	3		1	2	1	1			1	1			6	6
25				1	1										1	1
26												2			0	2
27	1		5		1										7	0
29			3			1	2		1	1					6	2
37					1								1		2	0
48		1			1	1	1	5		1					2	8
52					3		4								7	0
53			1		1		2	3							4	3
54	1		4		6		2	3		1		1			13	5
Subtotal	3	3	31	10	36	16	34	28	10	13	9	6	3	2	126	78
Total	6		41		52		62		23		15		5		204	

M: Male F: Female

The ratio applied to the cells within the base grid to construct the quota grid for the general public recruitment approach was 1:4, on the basis of an anticipated response rate of approximately 25%, which would achieve the desired sample size of approximately 200 general public participants. However, since previous research has suggested that young people, especially young men, may be less likely to respond to social surveys (Bowling, 1997a) a ratio of 1:8 was used for the lowest age band of 20-29 years.

As shown in Table 8.6, this produced a requirement to approach 840 members of the public (516 males and 324 females) aged between 20 and 89 years (the highest proportion of which were 30-69) within the designated postcodes.

Table 8.6: General Public Recruitment Grid by Age, Gender and Postcode District

Postcode District	Age Bands (years)															
	20-29		30-39		40-49		50-59		60-69		70-79		80-89		Total	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F
4							4		16						20	0
6			12			4		24				4			12	32
7									4	12	12			8	16	20
8					4			16	4	4					8	20
9										4					0	4
10	8		4	4	4	4									16	8
11			12		4		28								44	0
12			4		4			4							8	4
14			8		16		4								28	0
15					20	12	24	4		8					44	24
16							4			4		4	8		12	8
17					4	24		4							4	28
19			4	8	4			4			4				12	12
22			16	24	16	4	20	8	8	8	16				76	44
23					8		4		4						16	0
24		16	12		4	8	4	4			4	4			24	32
25				4	4										4	4
26												8			0	8
27	8		20		4										32	0
29			12			4	8		4	4					24	8
37					4								4		8	0
48		8			4	4	4	20		4					8	36
52					12		16								28	0
53			4		4		8	12							16	12
54	8		16		24		8	12		4		4			56	20
Subtotal	24	24	124	40	144	64	136	112	40	52	36	24	12	8	516	324
Total	48		164		208		248		92		60		20		840	

M: Male F: Female

In other contexts, the instrument that would be appropriate for use with adult members of the general public would be the WHOQOL-BREF (or the longer WHOQOL-100). Although the current research design called for a between groups comparison in relation to the adapted instrument, the WHOQOL-ID, the use of general public participants as the third research group provided the opportunity for a comparison of the two versions of the instrument also. Therefore it was decided to present half of the potential public participants in each age/gender/locality cell with study packs containing the adapted 36-item WHOQOL-ID, and present the other half of the potential public participants with packs containing the original 26-item WHOQOL-BREF with the ten 'social justice' items (described in Chapters 5 and 6) added as a supplementary module. Thus 420 members of the public (258 males and 162 females) were approached in relation to each version of the instrument, as shown in Table 8.7.

Table 8.7: General Public Recruitment Grid for WHOQOL-ID and WHOQOL-BREF

Postcode District	Age Bands (years) 20-29		30-39		40-49		50-59		60-69		70-79		80-89		Total	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F
4							2		8						10	0
6			6			2		12				2			6	16
7									2	6	6			4	8	10
8					2			8	2	2					4	10
9										2					0	2
10	4		2	2	2	2									8	4
11			6		2		14								22	0
12			2		2			2							4	2
14			4		8		2								14	0
15					10	6	12	2		4					22	12
16							2			2		2	4		6	4
17					2	12		2							2	14
19			2	4	2			2			2				6	6
22			8	12	8	2	10	4	4	4	8				38	22
23					4		2		2						8	0
24		8	6		2	4	2	2			2	2			12	16
25				2	2										2	2
26												4			0	4
27	4		10		2										16	0
29			6			2	4		2	2					12	4
37					2								2		4	0
48		4			2	2	2	10		2					4	18
52					6		8								14	0
53			2		2		4	6							8	6
54	4		8		12		4	6		2		2			28	10
Subtotal	12	12	62	20	72	32	68	56	20	26	18	12	6	4	258	162
Total	24		82		104		124		46		30		10		420	

M: Male F: Female

Given the amount of data to be collected (demographic questions plus quality of life items) it was expected that the response rate might be relatively low. However, although a commensurately low target response rate of 25% was set, (to provide a public group of around 200 participants), this was achieved in some but not all grid cells from the first tranche of 840 potential participants. A total of 81 completed questionnaires were returned from study pack version 1 (WHOQOL-ID), and 87 completed questionnaires were returned from study pack version 2 (WHOQOL-BREF), providing overall response rates of 19% and 21% respectively. However, the individual grid cell response rates ranged from zero to 33% for both versions.

In order to achieve an adequate sample in terms of both overall number and appropriate distribution by gender, age and postcode, a second round of recruitment was undertaken, focussing on the underrepresented grid cells for each study pack version (defined by first round response rates < 20%).

The second round of general public participant recruitment was undertaken in exactly the same manner as the first round (through blind access to the CHI etc) with sampling parameters adjusted, in two stages[8], taking account of the achieved first round returns.

In stage one, the percentage return from the first recruitment round was calculated for each ten-year age band by gender across all postcodes; and the formula applied to estimate the overall size of the second participant pool required, based on the previously achieved average response rate of 20% was:

Second participant pool = (target participants by version – first round returns by version)*5

This produced a requirement to approach a further 206 members of the public (172 males and 34 females) within the gender and age bands shown in table 8.8. Although similar *total* numbers of returns were achieved for both versions of the study pack in the first recruitment round, the pattern of below criterion response rate by grid cell differed by pack, such that 127 (62%) of the second tranche of potential public participants were linked with the WHOQOL-ID study pack and 79 (38%) were associated with the WHOQOL-BREF study pack.

Table 8.8: Second Round Recruitment of General Public by Age, Gender and Version

Version of Study Pack	Age Bands (years)															
	20-29		30-39		40-49		50-59		60-69		70-79		80-89		Total	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F
WHOQOL-ID		8	33		30		30			13	8			5	101	26
WHOQOL-BREF		8	53						10				8		71	8

M: Male F: Female

In stage two, the overall numbers in the second general public participant pool, within the required gender and age groups for each version of the study pack, were distributed between the underrepresented postcode districts proportionate to deficit, as shown in Tables 8.9 and 8.10. Of the 25 postcode districts represented in the original general public participant recruitment grid, 20 (80%) featured in the second tranche public recruitment also: 18 (72%) in relation to study pack version 1 (WHOQOL-ID) and 14 (56%) in respect of study pack version 2 (WHOQOL-BREF). Of these 20 postcodes, 12 (60%) were common to both study pack versions; 6 (30%) were associated with the WHOQOL-ID only; and 2 (10%) were linked to the WHOQOL-BREF only.

[8] This two-step procedure was undertaken to simplify calculations and avoid either over-inflating (by rounding up fractions) or under inflating (by rounding down fractions – sometimes to zero) the requirements for the second participant pool from estimations based on the combination of three grid cell variables (i.e. age, gender and postcode).

Table 8.9: Second Round Recruitment Grid for WHOQOL-ID

Postcode District	Age Bands (years)							Total	
	20-29	30-39	40-49	50-59	60-69	70-79	80-89		
	F	M	M	M	F	M	F	M	F
6		11						11	0
7					4	3	5	3	9
8			2					2	0
10			2					2	0
11			2	18				20	0
12		4	2					6	0
14				3				3	0
16					2			0	2
17			2					2	0
19		4	2					6	0
22					3	4		4	3
23			4	3				7	0
24	5		2	3		1		6	5
25			2					2	0
29		10						10	0
48	3			3	2			3	5
53		4						4	0
54			10		2			10	2
Subtotal	8	33	30	30	13	8	5	101	26
Total								127	

M: Male F: Female

Table 8.10: Second Round Recruitment Grid for WHOQOL-BREF

Postcode District	Age Bands (years)				Total	
	20-29	30-39	60-69	80-89		
	F	M	M	M	M	F
4			4		4	0
7			2		2	0
8			2		2	0
12		3			3	0
14		6			6	0
16				5	5	0
19		3			3	0
22		10			10	0
24	5	9			9	5
29		9	2		11	0
37				3	3	0
48	3				0	3
53		3			3	0
54		10			10	0
Subtotal	8	53	10	8	71	8
Total					79	

M: Male F: Female

In the second round of public participant recruitment, a total of 22 completed questionnaires were returned from study pack version 1 (WHOQOL-ID), and 18 completed questionnaires were returned from study pack version 2 (WHOQOL-BREF), providing overall response rates of 17% and 23% respectively. However, once again there was considerable variation in the individual grid cell response rates, ranging from 6% to 40%.

As shown in Table 8.11, a total of 1,046 members of the general public were approached to participate in the study across the two tranches of recruitment. Although 42 study packs (4% in each recruitment tranche) were returned 'undelivered' by the post office or by a householder marked 'unknown at this address', replacement packs were sent out to additional potential participants matching the characteristics of these unavailable individuals, maintaining the numbers approached to participate in the study at the designated level. However, thirteen of the study packs (1.2%) were returned to the research office opened but unmarked, presumably sent back by the intended recipient.

Table 8.11: General Public Group Recruitment and Exclusions by Gender and WHOQOL Version

Gender	Participant Pool (*N*)			Non-Consent		Completed Assessments	
	T1	T2	Total	*N*	%	*N*	%
Male	516	172	688	109	~ 15.8	123	~ 17.9
Female	324	34	358	67	~ 18.7	83	~ 23.2
Unknown	-	-	-	2	-	2	-
ID	420	127	547	96	17.6	103	18.8
BREF	420	79	499	82	16.4	105	21.0
Total	840	206	1,046	178	17.0	208	19.9

T1 = First Tranche T2 = Second Tranche ~ Approximate Values

Of the *total participant pool*, 208 members of the general public (20% of those approached) participated in the study: 123 (59%) were male; 83 (40%) were female; and 2 (1%) declined to provide gender information. Although the overall response rate was 20%, there were slightly more female respondents (approximately 23%) than males (approximately 18%); and slightly more returns from participants completing the WHOQOL-BREF version of the study pack (21%) than those completing the WHOQOL-ID version of the pack (19%). A further 178 members of the public (17%) were excluded from the study following their informed refusal to participate: 109 (61%) were male; 67 (38%) were female; and 2 (1%) declined to provide gender information. Finally, 647 of the individuals approached (62%) made no response, neither completing the questionnaire or the refusal form provided, nor returning the study pack.

Summary of Final Group of Participants

417 adults with intellectual disabilities participated in the main study (213 hospital residents and 204 community clients). The WHOQOL-ID version of the assessment pack was completed by, or on behalf of, this group of participants, within the context of a face-to-face interview. A summary of these participants by response mode is presented in in Table 8.12.

Table 8.12: ID Participants by Response Mode

Response Mode	Respondent	Hospital (*N* = 213)		Community (*N* = 204)		Total ID (*N* = 417)	
		N	%	*N*	%	*N*	%
Direct	Client	17	8.0	10	4.9	27	6.5
	Client + Staff Combined	11	5.1	36	17.6	47	11.3
Total Direct		28	13.1	46	22.5	74	17.7
Indirect	Staff proxy	185	86.9	158	77.5	343	82.3

A total of 74 ID clients (18%) participated in the study directly, either individually or with the support of staff; and proxy staff participated on behalf of the remaining 343 (82%) of ID clients. The balance of direct and indirect participation was broadly similar across the two of care type subgroups, but overall a larger proportion of community clients (23%) participated directly compared with hospital residents (13%). However, a slightly larger proportion of hospital residents (8%) participated directly and individually compared with community clients (5%); and a slightly larger proportion of community clients participated directly with staff support (18%) compared with hospital residents (5%).

In addition, 208 members of the general public participated in the main study, of whom 103 (50%) completed the WHOQOL-ID version of the study pack, and 105 (50%) completed the WHOQOL-BREF version of the study pack, within the context of a postal survey.

Characteristics of Participants

The demographic data on participants were collected as part of the introductory section of the final main study version of the WHOQOL assessment booklet. Two participants in the general public group (1%) returned the relevant assessment booklet anonymously, with this introductory section remaining blank, despite having completed other sections of the included measures. Therefore, it should be noted that many of the tables that follow indicate two missing cases for this group, representing these same two participants on each occasion.

Gender

Overall, approximately 60% of the participants were male and 40% were female.

Table 8.13: Participants by Gender

Gender	Hospital		Community		General Public		Total Group	
	N	%	*N*	%	*N*	%	*N*	%
Male	131	61.5	126	61.8	123	59.7	380	61.0
Female	82	38.5	78	38.2	83	40.3	243	39.0
	(*N* = 213)		(*N* = 204)		(*N* = 206)		(*N* = 623)	

Missing cases: General public = 2

As shown in Table 8.13, these proportions were reproduced across all three of the research groups, suggesting that adequate matching had been achieved on this variable. A 3*2 chi-square test confirmed that there was no significant difference between the groups on the basis of gender ($\chi^2 = 0.217$, $df = 2$, $p = 0.897$).

Age

Overall, and within the index community group, approximately half of the participants were aged below 50 years and half were aged 50 or above. However, as shown in Table 8.14, a slightly higher proportion (60%) of the hospital group were below 50, and a slightly higher proportion of the general public group (55%) were 50 or over.

Table 8.14: Participants < and ≥ 50 years

Age	Hospital		Community		General Public		Total Group	
	N	%	*N*	%	*N*	%	*N*	%
< 50	127	59.6	99	48.5	92	44.7	318	51.0
≥ 50	86	40.4	105	51.5	114	55.3	305	49.0
	(*N* = 213)		(*N* = 204)		(*N* = 206)		(*N* = 623)	

Missing cases: General public = 2

The age range of participants was very large and extended across the span of adulthood from 20 to 98 years. The oldest participant was a hospital resident (rather than a non-intellectually disabled member of the general population) demonstrating the increase in lifespan of individuals with intellectual disabilities noted by researchers in recent years (e.g. Hogg et al, 2000).

The mean age of all participants was 50.2 years (*SD* 13.4). As shown in Table 8.15, the mean age of hospital residents was 48.4 (range 23-98), the mean age of community clients was 50.7 (range 27-86) and the mean age of the general public was 51.5 (range 20-81). These data suggested that despite the slight variation in proportions of participants above and below 50 years, adequate matching might have been achieved on this variable also. A one-way analysis of variance produced an F value close to significance ($F_{2, 620} = 3.031$, $p=0.049$). As the numbers in each group were not equal, Welch's statistic was applied and this produced a marginal but non-significant p value ($p=0.055$).

Table 8.15: Participants by Age

Group	*N*	Age Range	Mean Age	*SD*
Hospital	213	23 - 98	48.4	± 13.86
Community	204	27 - 86	50.7	± 13.04
General Public	206	20 - 81	51.5	± 13.17
Total Group	623	20 - 98	50.2	± 13.41

Missing cases: General public = 2

Multiple *t*-tests would not normally be undertaken in relation to three groups in order to avoid inflating the Type I error rate (Hair, et al 1998). However, in the light of the ANOVA results, subsequent *t*-tests were undertaken to provide further information. The *t*-test results indicated that there was no significant difference between the two groups of ID clients living in hospital and in the community ($t = 1.709$, $df = 415$, $p = 0.088$, two-tailed, variances equal) and no significant difference between the community clients and the general public, both living in the community ($t = 0.659$, $df = 408$, $p = 0.511$, two-tailed, variances equal).

For the purposes of the present study (and given the participant recruitment constraints outlined in Chapter 4) this cumulative evidence suggested overall that an adequate match had been achieved between the three groups of participants on the variable of age, albeit that this match was more clearly defined between the community and public groups, than between the community and hospital groups.

Locality

The projects in which the community clients resided were located in 25 community neighbourhoods, as defined by the first two digits of the address postcode. General public participants were recruited from these 25 postcode districts also, but in addition, two members of the public group (1%) returned contact information showing addresses within neighbouring postcode districts i.e. from non-matching and therefore non-sought postcodes.

The full distribution of these two groups of participants by postcode district is presented in Table 8.16. Overall, similar proportions of participants from the two research groups were represented within each postcode, but slightly more community clients than general public resided in postcode district 22 in the South of the study region, and slightly more general public than community clients resided in postcode district 54 in the west of the region.

A 27*2 chi-square test was attempted to test the match between the two groups on postcode locality, but many cells were found to have low expected frequencies (38.9% of cells with expected counts < 5) and the resulting chi square statistic was likely to be an overestimate and therefore unreliable.

Table 8.16: Community Clients and General Public Participants by Postcode District

Post Code	Community Clients		General Public	
(First 2 Digits)	*N*	%	*N*	%
4	5	2.5	6	2.9
6	11	5.4	9	4.4
7	9	4.4	12	5.8
8	7	3.4	5	2.4
9	1	0.5	2	1.0
10	5	2.5	5	2.4
11	11	5.4	9	4.4
12	3	1.5	1	0.5
14	7	3.4	9	4.4
15	17	8.3	18	8.7
16	5	2.5	4	1.9
17	8	3.9	9	4.4
19	6	2.9	3	1.5
20	-	-	1	0.5
22	30	14.7	19	9.2
23	4	2.0	5	2.4
24	12	5.9	10	4.9
25	2	1.0	4	1.9
26	2	1.0	4	1.9
27	7	3.4	5	2.4
29	8	3.9	7	3.4
37	2	1.0	3	1.5
39	-	-	1	0.5
48	10	4.9	13	6.3
52	7	3.4	6	2.9
53	7	3.4	10	4.9
54	18	8.8	26	12.6
Total	204	100.0	206	100.0

Missing cases: General public = 2 Blue: Non-matching (unsought) postcodes

Subsequently, the 27 postcodes were combined to form six larger postcode areas, in which the original postcode districts were aggregated according to the local agencies shared common service boundaries. These areas, shown in Table 8.17, were locally determined and based on roughly equivalent populations within the city centre quadrants and the areas surrounding the city.

Table 8.17: Community Clients and General Public Participants by Aggregated Postcodes

Post Code Areas (Aggregated Districts)		Community Clients		General Public	
		N	%	*N*	%
City Centre Areas:					
1	NW	16	7.8	14	6.8
2	NE	37	18.1	39	18.9
3	SE	21	10.3	20	9.7
4	SW	23	11.3	23	11.2
Peripheral Areas:					
5	West	49	24.0	60	29.1
6	South	58	28.4	50	24.3
	Total	204	100.0	206	100.0

Missing cases: General public = 2

A further 6*2 chi-square carried out on this contingency table confirmed that an adequate match on the variable of locality had been achieved, as there was no significant difference between the two groups on the basis of these postcode areas ($\chi^2 = 1.903, df = 5, p = 0.862$).

Education

The highest level of education received by participants is presented in Table 8.18. As found in pilot study two (Chapter 6), the educational background of almost 40% of the adults with intellectual disabilities in both hospital and community groups was unknown.

Table 8.18: Participants by Highest Level of Education

Education	Hospital		Community		General Public	
	N	%	*N*	%	*N*	%
None	55	25.8	28	13.7	3	1.5
Primary school	3	1.4	7	3.4	-	-
Secondary school	4	1.9	1	0.5	132	66.3
Special school	70	32.9	88	43.1	3	1.5
Tertiary	-	-			61	30.7
Not known	81	38.0	80	39.2	-	-
Total	213	100.0	204	100.0	199	100.0

Missing cases: General public = 9 (2 Anon, plus additional 7)

Almost twice as many of the hospital group (26%) were reported to have received no education compared with the community group (14%). At face value, this might seem a surprising result, given the similarity of the background

of the ID clients. However, this finding may be accounted for by the fact that Hospital A (in which the community clients resided formerly) had a special school on the campus, but Hospital C (despite its early history as an educational establishment), did not appear to have such a facility. Consistent with this was the finding that a higher proportion of the community clients had attended special school (43%) compared with hospital residents (33%).

Approximately two thirds of the general public group had attended secondary school, with almost one third having proceeded to tertiary education. However, three general public participants (1.5%) reported 'None at all' as their highest level of education. These individuals were all female; aged between 27 and 52; two were in paid employment; and one was retired. The balance of probability suggested that this was an unlikely finding and it may reflect simple errors in item completion rather than actual educational deficit.

A further three general public participants (1.5%) reported 'Special School' as their highest level of education. These individuals were all male; aged between 26 and 55; two were attending 'Day Centres'; and one had indicated that he had received help to complete the questionnaire items. This suggested that at least some of these individuals might have an intellectual disability, and thus there might be a small overlap between the set of the general public and the set of community clients.

Marital Status

The findings on marital status were starkly different for the adults with intellectual disabilities compared with the general public. Almost all (99.5%) of the hospital and community group participants were single. This finding was consistent with that of the pilot study, in which 100% of the ID participants were single also. In the main study group, the finding that one individual in each of the hospital and community groups had been married formerly was the more exceptional outcome.

Table 8.19: Participants by Marital Status

Status	Hospital		Community		General Public	
	N	%	*N*	%	*N*	%
Single	212	99.5	203	99.5	23	11.2
Married	-	-	-	-	145	70.4
Living as married / couple	-	-	-	-	9	4.4
Separated	-	-	-	-	3	1.5
Divorced	-	-	1	0.5	11	5.3
Widowed	1	0.5	-	-	15	7.3
Total	213	100.0	204	100.0	206	100.0

Missing cases: General public = 2

In contrast, 11% of the public were single, 75% were married, or living as married, a further 7% were separated or divorced and 7% were widowed.

Health

As shown in Table 8.20, the majority of participants in the main study (approximately 83% overall) were in good health, with no significant difference between the three groups in reported health status ($\chi^2 = 2.851$, $df = 2$, $p = 0.240$).

The participants who reported something wrong with their health cited a wide range of illnesses and problems from colds and 'flu, to cardiac conditions and mental health problems, but all with very low percentage rates, and with no particular problem predominating.

Table 8.20: Participants by Health Status

Ill or Poor Health	Hospital		Community		General Public	
	N	%	*N*	%	*N*	%
Yes	31	14.6	42	20.6	33	16.2
No	182	85.4	162	79.4	171	83.8
Total	213	100.0	204	100.0	204	100

Missing cases: General public = 4 (2 Anon, plus additional 2)

Occupation

The introductory section of the main study version of the WHOQOL-ID (unlike the pilot version) included an item about 'main occupation or daytime activity'.

As shown in Table 8.21, the picture that emerged in relation to the general public participants was fairly conventional given the demographics: 63% were in paid employment; 24% were retired; approximately 10% were split in varying proportions between other types of occupation including voluntary employment, education, and home based activities; and only 3% of the public participants reported no daytime activity.

The majority of community clients either attended a day centre (54%), engaged in home based activities (22%), or took part in community activities (15%). Four individuals (2%) attended therapies programmes and two (1%) were in voluntary employment, but no community client was in further education or had a paid job. A similar proportion of the community clients as general public participants reported no daytime activity (5%).

In contrast, the majority of the hospital group (52%) reported no daytime activities. Most of the residents who were occupied during parts of the day attended various campus-based therapy programmes (38%) or home (ward)

based activities (6%). No hospital residents were engaged in paid employment or community activities, although small proportions were in voluntary employment (1%), an education setting (1%), or attended day centres (2%).

Table 8.21: Participants by Occupational Status

Occupation / Daytime Activity	Hospital		Community		General Public	
	N	*%*	*N*	*%*	*N*	*%*
Paid employment	-	-	-	-	129	62.6
Voluntary employment	2	0.9	2	1.0	3	1.5
Education/Further education	3	1.4	-	-	5	2.4
Community based activities	-	-	31	15.2	-	-
Home based activities	13	6.1	45	22.1	11	5.3
Day centre	4	1.9	111	54.4	2	1.0
Therapies programme	80	37.6	4	2.0	-	-
Retired	1	0.5	-	-	49	23.8
None	110	51.6	11	5.4	7	3.4
Total	213	100.0	204	100.0	206	100

Missing cases: General public = 2

The data reported on retirement was markedly different for adults with intellectual disabilities and members of the general population. 24% of the public group participants were aged 60 or over, and consistent with this, 24% reported that they had retired from formal occupation. However, although a similar proportion (22%) of both the community and hospital groups were aged 60 or over, no community client and only one hospital resident was reported to have retired. It is possible that adults with intellectual disabilities and their support staff view occupation and retirement differently to members of general public (valuing participation in structured activities for longer, assuming individual capacity permits this) or it may be that differential aspiration (in respect to achievement or occupational outcome) provides a framework for this continuing activity. However, it is conceivable that proxy staff providing information on behalf of ID client participants may have 'misreported' information on daytime activity also, as a result of applying an idiosyncratic classification to the presence or absence of occupation.

8.3 Dependency Measures

Three dependency measures were used to assess the match between the hospital and community groups of adults with intellectual disabilities: the Wessex Schedule (SPI and SSL subscales); the Degree of Dependency Rating Scale (DDRS) derived from the Wessex Schedule; and the Dependency and Needs Information System (DANIS). These instruments were described in Chapter 4 and presented in full in A4.3 to A4.5 (Wessex Schedule), A4.6 (derived DDRS) and A4.7 to A4.9 (DANIS), all in Appendix 4.

Background

For the majority of the adults with intellectual disabilities, dependency measures had been included in the key data collected as part of the preparation for resettlement to the community, and were made available for use in the study. In Hospital A (the former residence of 81% of the community group) the DDRS had been used for all residents; and additionally, the DANIS had been used for those residents remaining in hospital when the measure was introduced to pilot sites (approximately half way through the closure programme). In Hospital C (the contemporaneous residence of the hospital group) the DANIS only had been used for all residents. Although dependency was not an independent variable within this study design, it was an important matching variable for the two groups of adults with intellectual disabilities in terms of the three level independent variable (research group) comparison on the dependent variable (quality of life).

In order to determine the adequacy of the between groups match on dependency a consistent measure was required across the groups. The DDRS was selected as the main dependency measure for this purpose, as it offered the additional advantage of providing a 'time matched' dependency measure i.e. by employing the DDRS with the hospital group, pre-discharge dependency levels could be captured for both the hospital and community groups. In contrast, the use of the DANIS with the community group would provide post-discharge dependency levels for these individuals (if data were collected for all clients as part of the study) or a mixture of pre- and post-discharge levels (if data were collected only for those clients not assessed pre-discharge). Although for many of the adults with intellectual disabilities, basic levels of dependency might be expected to be similar at either time point (see Chapter 2), given the demographics of the index community clients, changes in dependency over time could not be ruled out for some individuals, as a result of the normal aging process and/or the impact of ID client specific conditions (e.g. early onset dementia). Therefore, the DDRS matched time point dependency levels provided for a more robust test of the similarity or difference of these two ID client groups. In addition, while both the Wessex based DDRS and the DANIS were designed as dependency measures linked to service planning, the DDRS ratings were more descriptive of client characteristics than the equivalent DANIS categories, which were more overtly weighted towards financial contracting (for details see Appendix 4).

In relation to Hospital B (the former residence of 19% of the community group) no dependency data were available. Thus, for 39 community clients, new dependency assessments were required, irrespective of the measure selected. Therefore, the issue for this group of adults with intellectual disabilities (9% of the total) was the extent to which the concept of matched time point dependency might be violated if the DDRS were selected for group matching on dependency. However, it transpired that this group of 39 clients tended to have been in the community for relatively short periods at the time of the study.

Table 8.22: Community Group by Length of Community Residence

Length of Stay In Community	Ex-Hospital A		Ex-Hospital B	
	N	%	*N*	%
2 years	20	12.1	21	53.8
3 years	64	38.8	7	17.9
4 years	36	21.8	2	5.1
5 years	28	17.0	6	15.4
6 years	17	10.3	3	7.7
Total	165	100.0	39	100.0

Twenty-one people (54%) had transferred to the community within the preceding two years (compared with only 12% of former Hospital A residents) and 28 individuals (72%) had transferred within the preceding 3 years, as shown in Table 8.22.

Furthermore, as shown in Table 8.23, 26 individuals (67%) were below 50 years of age (compared with only 44% of the former Hospital A residents) and only 13 were within the age bands that might be most prone to deterioration in capacity, and hence increased dependency, due to ageing.

Table 8.23: Community Group by Age

Age	Ex-Hospital A		Ex-Hospital B	
	N	%	*N*	%
< 50	73	44.2	26	66.7
≥ 50	92	55.8	13	33.3
Total	165	100.0	39	100.0

Therefore, on balance, the data on age and community transfer time for this group tended to support the selection of the DDRS as the main comparator dependency measure.

Collection of Dependency Data

The procedures undertaken to obtain available dependency data or complete new dependency assessments (as appropriate) were common to both hospital and community groups.

Pre-Existing Dependency Data

Pre-discharge levels of dependency on the DDRS were available for the community group who were the former residents of Hospital A; and pre-discharge levels of dependency on the DANIS were available for the hospital group who were cotemporaneous residents of Hospital C. These data were collected by staff (nurse key workers) as part of the relevant hospital's resettlement programme, and were made available for use in the research by agreement with the Medical Records Department and the Managers of the responsible NHS Trusts.

In addition, pre-discharge levels of dependency on the DANIS were available for some of the community clients who were the former residents of Hospital A. These data were collected by staff (also nurse key workers) within the context of the piloting of the DANIS measure by the Information and Statistics Division (ISD) of the National Health Service in Scotland, and were made available for use in the research by agreement with ISD and the Medical Director of the responsible NHS Trust.

New Dependency Assessments

New dependency assessments involved the completion of the Wessex Schedule items (from which the DDRS would be derived) by either nursing or social care staff (usually the key worker, or the member of staff who knew each ID client best) in the context of a face-to-face interview with a researcher. The interviews were arranged in advance and held in suitably comfortable, distraction-free settings (mostly staff offices, or small 'quiet rooms'); and appointments were set at times to suit each individual staff member, in order to minimise impact on their routine and avoid disruption to their usual pattern of work. At the start of the interview, the purpose of the assessment was outlined, the measure was introduced, and a general overview of the method of completion was presented. Subsequently, the assessment was completed in a standardised manner, with the items presented in sequence, the response to each item recorded, and the name and designation of the staff respondent noted on the record form.

Inter-Rater Reliability

New dependency assessments were required for the entire hospital group. As more than one researcher (the principal researcher and a research assistant) was involved in completing these assessments, inter-rater reliability procedures were undertaken in connection with 30 assessments (representing 10% of the 299 hospital residents at the time of planning, or 14% of the final group of 213 hospital residents). Two raters carried out these assessments simultaneously in vivo. In each case, the lead rater (an alternated role) interacted directly with the respondent (introducing the assessment and presenting the items) and both raters independently recorded responses, scored items and noted comments.

In the original work on the Wessex Schedule, Kushlick et al (1973) measured inter-rater reliability by means of simple percentage agreement rather than statistical correlation, on the basis that the scales contained relatively few points and it could not be assumed that scores were normally distributed. They also argued that as the scales primary use was categorisation, this method was more appropriate. They distinguished between two types of possible disagreement, major and minor, with minor differences defined as differences between adjacent categories only. The formula then applied was:

$$\text{Reliability} = \frac{\text{No Differences} \times 100}{\text{Minor Differences} + \text{Major Differences} + \text{No Differences}}$$

In the 1973 study, inter-rater reliability was reported for a sample of 100 individuals in hospital care. The data obtained indicated inter-rater reliability of 65% for the Social and Physical Incapacity scale (SPI) and 76% for the Speech, Self Help and Literacy scale (SSL). However, the authors acknowledged that their sample was unrepresentative, biased in favour of schedules completed by staff that may have had to complete large numbers of assessments in a short time, and was likely to have yielded 'a pessimistic picture of reliability'. For the purpose of comparison, the Kushlick formula was applied to the present study inter-rater reliability sample of 30 individuals, who were also in hospital care. These schedules were completed by trained personnel, in the context of face-to-face-interviews with respondent staff (during which any staff queries could be addressed), and therefore, higher levels of reliability would be expected. In fact, on the SPI, there were no differences between raters (neither major nor minor) producing inter-rater reliability of 100%; and on the SSL, there was one minor disagreement only producing inter-rater reliability of 96.7%.

However, the percentage agreement method of calculating inter-rater reliability does not take account of the amount of agreement that might be expected by chance. Therefore, Cohen's Kappa, a measure of concordance that does correct for chance agreement was used also. Robson (1993) has suggested that Kappa values between 0.4 and 0.6 are fair; between 0.6 and 0.75 are good; and above 0.75 are excellent. On this basis, the inter-rater reliability achieved for both the SPI ($K = 1.0$, $p < 0.001$) and SSL ($K = 0.916$, $p < 0.001$) was excellent.

Cohen's Kappa was used to calculate inter-rater reliability for the DDRS levels of dependency (derived from the Wessex items) also, and a similar high level of reliability was obtained ($K = 0.957$, $p < 0.001$).

New dependency assessments were required for thirty-nine clients in the community group also. However, as only one researcher (the principal researcher) carried out the dependency assessments in relation to these clients (who were the former residents of Hospital B) no inter-rater reliability procedures were required for this group.

Summary of Dependency Data

A summary of the dependency data collected by type, source and group is presented in Table 8.24.

Table 8.24: Dependency Assessments by Group

Measure	Source	Hospital Group		Community Group		Total ID	
		N	%	*N*	%	*N*	%
Wessex	New	213	100.0	39	19.1	252	60.4
DDRS	New	213	100.0	39	19.1	252	60.4
	Pre-existing	-	-	160	78.4	160	38.4
	Total	213	100.0	199	97.5	412	98.8
DANIS	Pre-existing	209	98.1	99	48.5	308	73.9
		(*N* = 213)		(*N* = 204)		(*N* = 417)	

Wessex missing data: Community group 165 DDRS missing data: Community group = 5
DANIS missing data: Hospital group = 4, Community group = 105

Wessex Schedules were completed for 252 (60%) of the ID clients; and related DDRS data were collected for 412 (99%) of the ID clients. In addition, DANIS data were available for 308 (74%) of the ID clients. These data were used for a between groups comparison to test the match between hospital residents and community clients on the variable of dependency; and a within subjects cross sectional correlation to determine the degree of association between the two dependency measures.

Dependency Match

The DDRS (derived from raw scores on the core Wessex items) provided the main data for determining the similarity or difference between the hospital and community groups on level of dependency. However, the SPI and SSL subscales produced by the new Wessex assessments were used to carry out a subsidiary exploration of the match between the hospital group and the small group of community clients transferred from Hospital B[9]; and the pre-existing DANIS data were used to explore the match between the hospital group and a subset of approximately two thirds of the larger group of community clients transferred from Hospital A[10] for whom these data were available also.

[9] A similar test could not be carried out for the larger group of community clients transferred from Hospital A, as raw Wessex data were not available for these clients.
[10] A similar test could not be carried out for the smaller group of community clients transferred from Hospital B, as DANIS data were not available for these clients.

Degree of Dependency Rating Scale

The degree of dependency categories of hospital residents and community clients as measured by the DDRS are presented in Table 8.25. Overall, the DDRS ratings showed that ID clients reflected the full range of dependency, with all dependency categories represented in the hospital group and eight out of nine categories represented in the community group. However, the trend was for ID clients in both settings to be represented in greater proportions within the higher dependency categories, as would be expected for that section of the ID population with a background in NHS residential care.

Table 8.25: Hospital Residents and Community Clients by DDRS Degree of Dependency

Degree of Dependency Category		Hospital		Community	
		N	*%*	*N*	*%*
1	Can and Able	8	3.8	25	12.6
2	Non-ambulant only	2	0.9	0	0.0
3	Severe behaviour problems only	24	11.3	3	1.5
4	Elderly low dependence	2	0.9	7	3.5
5	Elderly dependent	28	13.1	15	7.5
6	Medium dependence	23	10.8	42	21.1
7	High dependence	40	18.8	59	29.6
8	Severe behaviour problems - medium dependency	20	9.4	15	7.5
9	Severe behaviour problems - high dependency	66	31.0	33	16.6
	Total	213	100.0	199	100.0

Missing cases: Community clients = 5
CAN: Continent, Ambulant and No severe behaviour disorder Able: Self-help skills

A 9*2 chi-square test was attempted to test the match between the two groups on degree of dependency, but some cells were found to have low expected frequencies (22.2% of cells with expected counts < 5) and the resulting chi square statistic was likely to be an overestimate and therefore unreliable. Therefore, the nine dependency categories required to be combined in an appropriate manner and the test repeated.

The authors of the DDRS proposed the nine category method of aggregating the scores from the core Wessex items in order to avoid both the over simplistic CAN/CANT[11] dichotomy and the more complex thirty category system achieved by cross-classifying the six SPI ratings and the five SSL ratings derived from the original scale; and also to enhance the meaning of the resultant classification system for users (Caddell and Woods, 1984). However, they did not provide guidance on potential further reduction or appropriate combination of the nine DDRS dependency categories.

[11] In this system, CAN includes individuals who are continent, ambulant and not behaviour disordered and CANT includes all other individuals who have varying degrees of dependency in these areas.

The list format in which the nine categories were displayed in figure one of the original paper, running from *CAN and able* (clearly the least dependent category) to *severe behaviour problems – high dependency* (clearly the most dependent) could be construed as implying an ordinal arrangement of the categories. For seven of the nine categories there seemed to be face validity for this; however, the positioning of *severe behaviour problems only* and *elderly low dependence* appeared less straightforward.

Therefore, prior to taking forward category combination, the original definitions of the nine DDRS categories of dependency (shown at A4.6 in Appendix 4) were inspected and account was taken of the derivation of each category from sets of scores on relevant Wessex items. Following this, an attempt was made to reduce the nine dependency categories into three aggregated levels of dependency such as to introduce a 'smoothing' effect in relation to the problematic categories. Two possible combinations of categories were produced as shown in Table 8.26. The first reduced the nine categories to three following the implied ordinal arrangement; and the second introduced a variation based on a pragmatic interpretation of the *elderly low dependence* category as described below.

Table 8.26: Aggregation of Dependency Categories

Degree of Dependency Category	Aggregation (1)			Aggregation (2)		
	Low	Moderate	High	Low	Moderate	High
Can and Able	X			X		
Non-ambulant only	X			X		
Severe behaviour problems only	X			X		
Elderly low dependence		X		X		
Elderly dependent		X			X	
Medium dependence		X			X	
High dependence			X			X
Severe behaviour problems - medium dependency			X			X
Severe behaviour problems - high dependency			X			X

The DDRS category of *severe behaviour problems only* is assigned to dependency linked predominantly to the SPI category 'severely behaviour disordered' (in the presence of basic self-help skills and only minor or no problems of continence or mobility). In turn, the SPI 'severely behaviour disordered' category is derived from scores on a combination of five core Wessex items including *attention seeking* and *over activity* at the milder end of the problem behaviour spectrum as well as *aggression, destructiveness* and *self-injury* at the more severe end. Each of these behaviours is rated 'no' if the behaviour never occurs, or occurs so seldom as to be hard to remember the last occurrence; 'marked' if the behaviour has occurred in the past month; or 'lesser' if the behaviour appears to be between 'marked' and 'no'. Therefore, since this category depends on both mild to severe qualifying behaviour problems in the context of varying frequencies ranging from never to monthly, its positioning in

terms of level of dependency may be arguable; however, given the self-help, continence and mobility levels required to achieve this category, placement at the lower end of the dependency spectrum overall may be most appropriate

The DDRS category of *elderly low dependence* is assigned to dependency linked to a similar SPI profile (presence of basic self-help skills and only minor or no problems of continence or mobility) in the setting of older age and potential frailty, but without any reference to behaviour disorder. Thus it could be argued that this category fits best with the other age related category *elderly dependent* within a moderate level of dependency; however, in the context of a fit older person, placement at a lower level of dependency may be appropriate also.

From the category combinations thus derived, two further contingency tables were produced, as shown in Tables 8.27 and 8.28.

Table 8.27: Hospital Residents and Community Clients by Dependency Levels (1)

Dependency Level	DDRS Category Aggregation (1)			
	Hospital		Community	
	N	%	*N*	%
Low	34	16.0	28	14.1
Moderate	53	24.9	64	32.2
High	126	59.2	107	53.8
	213	100.0	199	100.0

Missing cases: Community clients = 5

It was considered that Table 8.27 might reflect the less robust of the category aggregations, as a result of the positioning of *severe behaviour problems only* in the 'low' dependency level, and *elderly low dependence* in the 'moderate' dependency level. However, on the basis of this dependency category aggregation, a 3*2 chi-square test confirmed that an adequate match on the variable of dependency had been achieved, as there was no significant difference between the hospital and community groups ($\chi^2 = 2.629$, $df = 2$, $p = 0.260$).

Table 8.28: Hospital Residents and Community Clients by Dependency Levels (2)

Dependency Level	DDRS Category Aggregation (2)			
	Hospital		Community	
	N	%	*N*	%
Low	36	16.9	35	17.6
Moderate	51	23.9	57	28.6
High	126	59.2	107	53.8
	213	100.0	199	100.0

Missing cases: Community clients = 5

It was thought that Table 8.28 might reflect the relatively more robust of the DDRS category aggregations, as the result of the positioning of both *severe behaviour problems only* and *elderly low dependence* in the 'low' dependency level. A 3*2 chi-square test confirmed that an adequate match on dependency had been achieved on the basis of this dependency aggregation also, as there was no significant difference between the hospital and community groups ($\chi^2 = 1.423$, $df = 2, p = 0.491$).

Therefore, as appropriate tests of the difference between groups on dependency levels based on both sets of category combinations produced non-significant results, for the purposes of the present study it was concluded that an adequate match had been achieved between the hospital and community groups on the variable of dependency as measured by the DDRS.

Wessex Subscales

The Wessex Social and Physical Incapacity (SPI) ratings and Speech, Self Help and Literacy (SSL) ratings of hospital residents and a subset of 39 community clients are presented in Table 8.29. Overall, the Wessex ratings also showed that the ID clients reflected the full range of dependency, with the hospital group distributed across all dependency categories on both Wessex subscales; and the community group distributed across five out of six categories on the SPI subscale, and four out of five categories on the SSL subscale.

Table 8.29: Hospital Residents and Community Clients by Wessex Subscale and Dependency Category

Wessex Subscale	Dependency Category	Hospital (*N* = 213)		Community (*N* = 39)	
		N	%	*N*	%
SPI	Non-ambulant	70	32.9	15	38.5
	Incontinent and behaviour disordered	37	17.4	6	15.4
	Behaviour disordered only	62	29.1	11	28.2
	Incontinent only	9	4.2	3	7.7
	Mildly incapacitated	25	11.7	4	10.3
	Not incapacitated (CAN)	10	4.7	0	0
SSL	No speech, self-help or literacy	140	65.7	31	79.5
	Verbal only	33	15.5	5	12.8
	Able only	6	2.8	1	2.6
	Able and verbal	21	9.9	0	0
	Literate	13	6.1	2	5.1

CAN: Continent, Ambulant and No severe behaviour disorder Able: Self-help skills

A 6*2 chi-square test was attempted to test the match between the two groups on SPI rating, and a 5*2 chi-square test was attempted to test the match between the two groups on SSL rating, but some cells were found to have low expected

frequencies (25% of cells with expected counts < 5 for the SPI contingency table and 30% of cells with expected frequencies < 5 for the SSL contingency table), and the resulting chi square statistics were likely to be overestimates and therefore unreliable.

Kushlick et al (1973) indicated that the six SPI categories could be combined to produce three levels of handicap: severe handicap (comprising four categories: non-ambulant, incontinent and behaviour disordered, incontinent only, and behaviour disordered only); mild handicap (comprising mildly incapacitated); and none (comprising not incapacitated). Similarly, the five SSL categories could be combined to produce three levels of handicap: severe handicap (comprising three categories: no SSL, verbal only, and able only); mild handicap (comprising able and verbal); and none (literate). However, the resultant two 3*2 tables produced by combining the dependency categories into three levels of handicap did not resolve the problem of low expected frequency counts: in both the SPI and SSL contingency tables, expected counts < 5 remained in respect of two of the six cells (33.3%).

Therefore the dependency categories were further combined to produce two 2*2 contingency tables (aggregating the small numbers in the groups of mild handicap and none) as shown in Table 8.30.

Table 8.30: Hospital Residents and Community Clients by Wessex Subscale and Aggregated Level of Handicap

Wessex Subscale	Aggregated Handicap Level	Hospital (*N* = 213)		Community (*N* = 39)	
		N	%	*N*	%
SPI	Severe Handicap	178	83.6	35	89.7
	Mild Handicap / None	35	16.4	4	10.3
SSL	Severe Handicap	179	84.0	37	94.9
	Mild Handicap / None	34	16.0	2	5.1

Missing cases: Community clients = 165

A series of further 2*2 chi-square tests carried out on these contingency tables confirmed that an adequate match on the variable of dependency had been achieved in respect of both the SPI and SSL ratings, as there was no significant difference between the two groups on the basis of the aggregated handicap levels (SPI: $\chi^2 = 0.961$, $df = 1$, $p = 0.327$; and SSL: $\chi^2 = 3.160$, $df = 1$, $p = 0.075$).

Dependency And Needs Information System

The dependency groups of hospital residents and community clients as measured by the DANIS are presented in table 8.31.

Table 8.31: Hospital Residents and Community Clients by DANIS Group

DANIS Group	Group Weights	Hospital		Community	
		N	%	*N*	%
1	0.6	16	7.7	6	6.1
2	0.8	52	24.9	17	17.2
3	1.0	49	23.4	42	42.4
4	1.2	73	34.9	28	28.3
5	1.4	19	9.1	6	6.1
Total		209	100.0	99	100.0

Missing cases: Hospital residents = 4, Community clients = 105

The relevant weighting factor was applied to each DANIS grouping, such that a mean dependency score could be derived for the hospital and community groups.

Table 8.32: Participants by Weighted DANIS Scores

Group	*N*	Mean	*SD*	Variance
Hospital	209	1.026	± 0.22	0.050
Community	99	1.022	± 0.19	0.037
Total Group	308	1.025	± 0.21	0.046

Missing cases: Hospital residents = 4, Community clients = 105

As shown in Table 8.32, the numbers in the two groups were unequal (although large) and the descriptive statistics indicated that the variances were unequal also. However, the larger variance was only larger by a factor of 1.35 (conforming to the rule of not being more that three times the smaller variance) and therefore it was legitimate to use a *t*-test to compare the means of the two groups, as the *t*-test remains sufficiently robust in these circumstances (Clark-Carter, 1997). The results of the *t*-test indicated no significant difference between these two groups of hospital and community clients on the basis of the DANIS weighted dependency scores ($t = 0.145$, $df = 220.289$, $p = 0.885$, two-tailed, variances unequal).

Relationship of Dependency Measures

Finally, the relationship between the DDRS and the DANIS, was investigated in the context of a within subjects cross sectional correlational design using Spearman's rho (as the basic data from both measures was categorical and ordinal). The extent of overlap between the dependency measures across participants in the hospital and community groups is presented in Table 8.33.

Table 8.33: Overlap of Dependency Assessments by Group

Measure	Hospital Group		Community Group		Total ID	
	N	%	*N*	%	*N*	%
DDRS	213	100.0	199	97.5	412	98.8
DANIS	209	98.1	99	48.5	308	73.9
DDRS + DANIS	209	98.1	98	48.0	307	73.6
	(*N* = 213)		(*N* = 204)		(*N* = 417)	

As shown, data from both measures were available for three-quarters of the ID clients, representing almost all the hospital residents and approximately half of the community clients. For these participants, a significant positive correlation was found between the DDRS and DANIS for the total group (rho = 0.353, $N = 307$, $p < 0.001$, two-tailed); and a significant positive correlation was found between the measures for the hospital group (rho = 0.386, $N = 209$, $p < 0.001$, two-tailed) and for the community group (rho = 0.258, $N = 98$, $p = 0.01$, two-tailed) also.

8.4 Subgroup Match

An analysis of the key variables of gender, age and locality of general public participants was carried out to explore the match between the two subgroups presented with the ID or the BREF version of the study pack.

Gender

As shown in Table 8.34, the gender balance within both the ID and BREF sub groups of the public was approximately 60% male and 40% female.

Table 8.34: General Public Subgroups by Gender

Gender	Subgroup 1 (WHOQOL-ID)		Subgroup 2 (WHOQOL-BREF)	
	N	%	*N*	%
Male	61	60.4	62	59.7
Female	40	39.6	43	40.3
Total	101	100.0	105	100.0

Missing cases: Subgroup 1 = 2

A 2*2 chi-square confirmed that there was no significant difference between subgroups on the basis of gender ($\chi^2 = 0.039$, $df = 1$, p = 0.844).

Age

The age range and mean age of general public participants in the two subgroups is presented in Table 8.35.

Table 8.35: General Public Subgroups by Age

Group	*N*	Age Range	Mean Age	*SD*
Subgroup 1 (WHOQOL-ID)	101	27-81	52.2	± 12.91
Subgroup 2 (WHOQOL-BREF)	105	20-80	50.9	± 13.46
General Public	206	20 - 81	51.5	± 13.17

Missing cases: Subgroup1 = 2

A *t*-test indicated that there was no significant difference between the subgroups on the basis of age ($t = 0.672$, $df = 204$, $p = 0.503$, two-tailed, variances equal).

Locality

The distribution of the two general public subgroups by aggregated postcode district is presented in Table 8.36.

Table 8.36: General Public Subgroups by Aggregated Postcodes

Post Code Areas (Aggregated Districts)		Subgroup 1 (WHOQOL-ID)		Subgroup 2 (WHOQOL-BREF)	
		N	%	*N*	%
City Centre Areas:					
1	NW	10	9.9	4	3.8
2	NE	18	17.8	21	20.0
3	SE	10	9.9	10	9.5
4	SW	12	11.9	11	10.5
Peripheral Areas:					
5	West	29	28.7	31	29.5
6	South	22	21.8	28	26.7
	Total	101	100.0	105	100.0

Missing cases: Subgroup 1 = 2

A 6*2 chi-square carried out on this contingency table confirmed that there was no significant difference between the subgroups on the basis of these localities ($\chi^2 = 3.556$, $df = 5$, $p = 0.615$).

8.5 Representativeness of Samples

Basic demographic information was collected on those individuals who declined to participate in the study, in order to conduct appropriate analyses in relation to possible sample bias. The data used for group matching on gender, age, dependency (adults with intellectual disabilities) and locality in terms of postcode district (community clients and members of the public) were available for this analysis. In addition, data on assessment version were available for the general public group.

Adults with Intellectual Disabilities

The rate of non-consent within both the hospital and the community groups was very low (1%) as shown in Table 8.37. Therefore a detailed statistical analysis of participants compared with refusers was neither feasible, nor required in relation to possible sample bias. However, brief details of the characteristics of the non-consenting individuals are presented for information.

Table 8.37: ID Participants and Refusers

Group	Participant Pool	Non-Consent		Completed Assessments	
	N	*N*	*%*	*N*	*%*
Hospital	216	3	1.4	213	98.6
Community	206	2	1.0	204	99.0
Total ID Clients	422	5	1.2	417	98.8

Gender and Age

All five adults with intellectual disabilities who refused to participate in the study were female.

The age of ID participants and refusers is presented in Table 8.38.

Table 8.38: ID Participants and Refusers by Age

Group	Subgroup	*N*	Age Range	Mean Age	*SD*
Participants	Hospital	213	23 - 98	48.4	± 13.86
	Community	204	27 - 86	50.7	± 13.04
Refusers	Hospital	3	27 - 85	50.7	± 30.44
	Community	2	60 - 69	64.5	± 6.36

As shown in Table 8.38, hospital participants and refusers were similar in terms of age range and mean age, although the standard deviation associated with the three refusers was larger. However, the community refusers were slightly older than community participants in terms of mean age and reflected the upper range of the age distribution only.

Dependency

All the ID refusers had the capacity to make their own decision about participation in the study, thus all were within the lower ranges of dependency.

As shown in Table 8.39, three individuals (two community clients and one hospital resident) had the lowest dependency rating of all (with no major adaptive deficits or maladaptive behaviours); one hospital resident was of medium dependency in the context of older age; and one hospital resident was of medium dependency associated with behaviour problems.

Table 8.39: ID Refusers by Dependency

Dependency Level	Degree of Dependency Scale Rating	Hospital *N*	Community *N*
1	CAN & Able	1	2
5	Elderly Dependent	1	-
8	SBP & Medium Dependency	1	-

CAN: Continent, Ambulant and No severe behaviour disorder Able: Self-help skills
SBP: Severe behaviour problems

General Public Adults

The rate of formal non-consent (refusal form returned) within the group of adult members of the general public approached to participate in the study was higher than that for adults with intellectual disabilities, with an overall rate of 17%, and similar proportions of males (16%) and females (19%) declining to take part in the study (see Table 8.11).

Gender

As shown in Table 8.40, the gender balance within both the participant and refuser groups was approximately 60% male and 40% female. A 2*2 chi-square confirmed that there was no significant difference between participants and refusers on the basis of gender ($\chi^2 = 0.175$, $df = 1$, $p = 0.676$).

Table 8.40: General Public Participants and Refusers by Gender

Gender	Participants		Refusers	
	N	%	*N*	%
Male	123	59.7	110	61.8
Female	83	40.3	68	38.2
Total	206	100.0	178	100.0

Missing cases: Participants = 2

Age

The age of participants and refusers is presented in Table 8.41. In some age bands the balance between participants and refusers was similar (e.g. for individuals in their 20s and 40s) but in other bands there appeared to be differences (e.g. more participants than refusers in their 50s, more refusers than participants in their 60s, 70s and 80s).

Table 8.41: General Public Participants and Refusers by Age

Age Band (Years)	Participants		Refusers	
	N	%	*N*	%
20-29	10	4.9	8	4.5
30-39	35	17.0	22	12.4
40-49	47	22.8	38	21.5
50-59	65	31.6	37	20.9
60-69	29	14.1	34	19.2
70-79	15	7.3	28	15.8
80-89	5	2.4	10	5.6
Total	206	100.0	177	100.0

Missing cases: Participants = 2, Refusers = 1

A 7*2 chi-square carried out on this contingency table confirmed that there was a significant difference between participants and refusers on the basis of their age in ten-year bands ($\chi^2 = 15.714$, $df = 6$, $p = 0.015$).

The mean age of general public participants and refusers is presented for the total groups and by gender subgroup in Table 8.42. These data suggested also that refusers trended to be slightly older than participants, and a t test confirmed that there was a significant difference between the two groups overall ($t = 3.021$, $df = 350.660$, $p = 0.002$, two-tailed, variances unequal).

Table 8.42: General Public Participants and Refusers by Age and Gender

Group	Gender	*N*	Age Range	Mean Age	*SD*
Participants	Male	123	20 - 80	49.5	± 13.56
	Female	83	26 - 81	54.6	± 12.03
	Total	206	20 - 81	51.5	± 13.17
Refusers	Male	110	21 - 81	55.9	± 15.33
	Female	67	21 - 81	56.2	± 15.17
	Total	177	21 - 81	56.0	± 15.23

Missing cases: Participants = 2, Refusers = 1

A further comparison between the gender subgroups revealed that there was no difference in the age of refusers on the basis of gender ($t = 0.141$, $df = 175$, $p = 0.888$, two-tailed, variances equal); however, female participants tended to be older than male participants ($t = 2.775$, $df = 204$, $p = 0.006$, two-tailed, variances equal).

WHOQOL Version

The rate of formal non-consent from adult members of the general public approached to participate in the study was similar for the versions of the study pack that included the WHOQOL-ID and WHOQOL-BREF (see Table 8.11).

Table 8.43: General Public Participants and Refusers by WHOQOL Version

Study Pack	Participants		Refusers	
	N	%	*N*	%
WHOQOL-ID	103	49.5	96	53.9
WHOQOL-BREF	105	50.5	82	46.1
Total	208	100.0	178	100.0

As shown in Table 8.43, the study pack balance between participants was approximately 50:50 (in line with the study design); but it appeared that a slightly larger proportion of refusers had been presented with the WHOQOL-ID (54%) compared with the WHQOL-BREF (46%). If significant, this finding might have been linked to the size of the WHOQOL-ID study pack (nine A4 pages including front cover and instructions) compared with the WHOQOL-BREF (eight A4 pages) as the required rewording of items, and the inclusion of prompts and examples, added to the overall length of the adapted measure. However, a 2*2 chi-square indicated that there was no significant difference between participants and refusers in relation to the assessment version received in the postal study pack ($\chi^2 = 0.748$, $df = 1$, $p = 0.387$).

Locality

A summary of the localities in which participants and refusers resided is presented in Table 8.44 by aggregated postcode districts. Overall, similar proportions of participants and refusers seemed to be represented within some areas, but there was more variation in other areas. For example, more refusers than participants appeared to reside in postcodes in the South of the study region; and more participants than refusers appeared to reside in postcodes in the west of the region. Superficially, these areas were quite similar: the South was a mixture of small towns and rural communities; and the West included a similar mix of small town and rural localities, together with one larger 'new town'.

A 6*2 chi-square carried out on this contingency table confirmed that there was a significant difference between the groups of participants and refusers on the basis of the aggregated postcode districts ($\chi^2 = 16.996$, $df = 5$, $p = 0.005$).

Table 8.44: General Public Participants and Refusers by Aggregated Postcodes

Post Code Areas (Aggregated Districts)		Participants		Refusers	
		N	%	*N*	%
City Centre Areas:					
1	NW	14	6.8	17	9.5
2	NE	39	18.9	32	18.0
3	SE	20	9.7	23	12.9
4	SW	23	11.2	18	10.1
Peripheral Areas:					
5	West	60	29.1	24	13.5
6	South	50	24.3	64	36.0
Total		206	100.0	178	100.0

Missing cases: Participants = 2

The age distribution of people approached as potential participants in these two areas differed considerably, as shown in Table 8.45.

Table 8.45: General Public Approached to Participate by Age and Area

Age	City 1		City 2		City 3		City 4		West 5		South 6		Total	
	N	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%
20 - 59	68	69.4	111	64.2	60	61.9	127	100	232	93.5	233	76.9	831	79.4
60 - 69	30	30.6	62	35.8	37	38.1	0	0	16	6.5	70	23.1	215	20.6
Total	98	100	173	100.0	97	100.0	127	100	248	100.0	303	100.0	1046	100.0

Overall, 80% of the potential participant pool was in the younger adult range from 20 to 59 years and 20% were in the older adult age range from 60-89 years. This distribution was driven by the requirement to match the community cohort by age and locality. In relation to the West area, 93.5% of the people approached as potential participants were in the younger adult age group (<60 years) and only 6.5% were in the older adult age group (≥60 years); whereas in the South area, 80% of those approached to take part in the study were in the younger age range and 23% were in the older range (over three times as many as in the West). Thus the differential response rates by postcode areas may be related to the findings on age i.e. that older potential participants were more likely to refuse to take part than younger individuals.

8.6 Method: Assessment of Quality of Life

The overarching methodology used for the main study was similar for both the adults with intellectual disabilities and the general public adults. However, the quality of life assessments were administered in the context of face-to-face interviews with the ID clients (or proxy staff on behalf of ID clients), and by self-completed postal questionnaire for the public as described below.

Measures

Two instruments were used to assess the quality of life of adults with intellectual disabilities: the WHOQOL-ID (main study version) as described in Chapters 4 and 6, presented at A6.13 in the associated Appendix 6, and reproduced in full in A8.18 in Appendix 8 for ease of reference; and the Life Experiences Checklist (LEC) as described in Chapter 4, and presented in full in A4.2 in Appendix 4.

Three instruments were used to assess the quality of life of general public adults: the WHOQOL-BREF as described in Chapter 4 and presented in full in A4.1 in Appendix 4 (half public group); the WHOQOL-ID (half public group); and the LEC (total public group). For ease of use within the framework of the postal survey, and in an attempt to maximise completion of all assessment components, the relevant instruments for the general public were presented in the form of an assessment booklet and the two versions of this are presented in A8.34 (LEC and WHOQOL-ID) and A8.35 (LEC and WHOQOL-BREF), both in Appendix 8.

WHOQOL-ID

The WHOQOL-ID was the key measure of quality of life and was used for both adults with intellectual disabilities and members of the general public. The data obtained from the main study were used to carry out a full evaluation of the psychometric properties of the new instrument, as well as for comparison of the quality of life of participants in the three research groups.

WHOQOL-BREF

The original WHOQOL-BREF was presented to one half of the public group only, as part of a split-half comparison (with general public participants) of the adapted 36-item WHOQOL-ID and the original 26-item WHOQOL-BREF with the ten 'social justice' items added as a supplementary module.

LEC

The LEC was used as a second quality of life measure common to all participants. This instrument has been used widely in intellectual disability resettlement studies in the UK, and normative data are available for a general population sample also.

Procedure for Adults with Intellectual Disabilities

The procedural elements of the main study were common to both hospital and community participants, and similar for direct and proxy respondents. Both the quality of life assessments were administered by face-to-face interview. The interviews were arranged in advance and held in the hospital wards and community projects in suitably comfortable, distraction-free settings (mostly small 'quiet rooms', or living rooms unused by others at the time). As for the pilot study, 'home-based' interview arrangements were made to maximise the likelihood of relaxed participation (Atkinson, 1988). Interview appointments were set at times to suit each individual ID client or staff proxy, in order to minimise impact on their routine, avoid disruption to their usual pattern of day activities or work, and maximise stress-free participation. As a result of this, the pattern of assessment appointments varied across wards and community projects: in some places only one interview was scheduled on a given day; but in others a set of interviews, with a range of respondents, was arranged on the same day.

Pre-interview

Before each interview appointment (or set of appointments), a check was made to ensure that the participant(s) had signed and returned the main study consent form; and participants were offered the opportunity to clarify any last minute points about the research purpose, the main study procedure, or use of the outcome data, in order to maximise their comfort with the task.

Assessment Order

The order of assessment administration was standardised for all participants, such that the LEC was the first assessment carried out and the WHOQOL-ID was the second assessment to be completed.

A priori this order was selected because the majority of the LEC items were objective in nature and required simple binary (yes/no) responses, and according to the LEC Manual (Ager, 1998), this assessment was likely to be the shorter of the two, with an average completion time of the order of ten minutes. In contrast, the WHOQOL-ID was the more subjective assessment, the items required a more complex response in terms of the five point Likert scales, and completion time was likely to be longer for this assessment, as the pilot study found mean completion times of 31 minutes for ID clients and 19 minutes for staff proxies (see Table 6.13, Chapter 6). Thus, participants were provided with the opportunity to complete the shortest and most straightforward scale first, with the aim of increasing their self-encouragement and commitment to continue with the remainder of the assessment procedure.

Some participants completed both assessments within the context of one interview; and other participants competed the assessments during two separate interviews. Exceptionally, one or more additional sessions were required for clients responding directly to the assessments (for example, one individual who communicated responses using a 'lightwriter').

Assessment 1: Life Experiences Checklist

During the first phase of the interview, the LEC was introduced; the method of completing the scale was presented and discussed in detail; and the participant identifier details were recorded at the head of the checklist.

The assessment was commenced and completed in the manner prescribed by the manual, following the structure of the LEC. Where required, evidence in the form of examples was sought to support responses, in order to judge accurately whether an item should be credited. The Coding Guide included in the LEC Manual was used to ensure consistent scoring of items; and following the interview, subscale and total scores were computed and entered on the record form.

Assessment 2: WHOQOL-ID

During the second phase of the interview, the WHOQOL-ID was introduced; a general overview of the method of completing the scale was presented; and the introductory socio-demographic section of the measure (About You) was completed.

Subsequently, the Instructions section was reviewed and explained in detail; and participants were invited to work through the non-scoring item example. This example was of particular importance in the case of clients designated by their carers as having the capacity to respond directly to this assessment, as it provided an opportunity for either confirmation of this capacity, or indication of the need for assistance.

The assessment was commenced and completed in a standardised manner, with respondents being asked to think about their life (direct clients) or the client's life (staff proxies) in the last two weeks. For each section, the introductory directions were read out, the questions were asked in sequence, and the participant's response to each item was noted on the record form. Finally, the method of assessment completion (direct or indirect), the name of the staff proxy (if applicable) and the time taken for the assessment was noted; and the respondent was invited to make comments about the questionnaire.

Post interview

Participants were thanked for taking part in the study and for giving their time and attention to the assessments. A few days after each interview, each participant was sent a short letter of thanks, an example of which is shown in A8.28 in Appendix 8.

For each client who participated in the study, a copy of the signed consent form was returned to the relevant care leader (hospital residents) or community project manager (community clients) as a record of the agreement to take part and the consenting respondent (client or staff proxy).

Procedural Variations

There was one procedural variation only, which related to the presentation of the WHOQOL-ID response scales for the two response modes: clients responding directly and staff responding on behalf of clients.

Clients

For clients responding directly to the WHOQOL-ID, the standard response scales were augmented with the appropriate set of 'smiley faces' (presented in full in A8.19 – A8.26 in Appendix 8). As described in Chapters 5 and 6, in recognition of the prevalence of visual impairment in the intellectual disabilities client group (Kerr et al, 1996), and in order to avoid possible confusion, these response scales were produced in large format and were presented one at a time, as required. The appropriate response scale was included in the question format for each item as part of the interview procedure, but additionally, and simultaneously, client respondents were directed to the correct response scale in order to better consider their answer. It was hoped that this methodology would reduce the occurrence of potential 'candidate answers' offered (and possibly changed) within the context of the brief pauses inevitable in the serial listing of response alternatives (Antaki and Rapley, 1996); and reduce the tendency to select the last option presented (Sigelman and Budd, 1986).

Proxy staff

To support the interview format, staff respondents were provided with a laminated prompt card on which the full range of WHOQOL-ID response scales (including numerical scale points and descriptors) were reproduced. The prompt card was introduced to reduce the necessity to repeat response scales if respondents required reminders of the options available for a particular item. The appropriate response scale was included in the question format for each item as part of the interview procedure, and in addition staff respondents were directed to the correct response scale on the prompt card as they considered their answer. The staff participant response scale card is shown A8.27 in Appendix 8.

Procedure for General Public

The procedural elements of the main study were common to both subgroups of general public participants. The two quality of life assessments were sent to potential participants in the context of a postal survey, and were presented in the form of an assessment booklet for self-completion. A stamped and addressed envelope was included for ease of return of the completed assessments.

Study Packs

As described in the section on the recruitment of general public participants, the assessment booklets were presented as part of 'study packs' containing a common set of elements as shown in Table 8.46. As shown, some information and documentation was specific to the version of the WHOQOL (ID or BREF) included, with approximately half of the general public participants receiving a WHOQOL-ID related pack; and half receiving a WHOQOL-BREF pack.

Table 8.46: Study Packs - General Public Participants

Study Pack Contents	Version (if applicable)	Reference in Appendix 8
Letter of invitation to participate from Director of Public Health	Single version	A8.29
Introductory covering letter from Researcher	Single version	A8.30
Participant Information Sheet	Single version	A8.31
Notification of Refusal Form	1: LEC & WHOQOL-ID	A8.32
	2: LEC & WHOQOL-BREF	A8.33
Quality of Life Assessment Booklet	1: LEC & WHOQOL-ID	A8.34
	2: LEC & WHOQOL-BREF	A8.35
Assessment Booklet Instruction Sheet (Printed on pink or blue coloured paper for ease of reference)	1: LEC & WHOQOL-ID	A8.36
	2: LEC & WHOQOL-BREF	A8.37
Stamped and addressed return envelope	N / A	-

Assessment Order

A consistent order of assessment presentation (as used for the ID participants) was maintained by situating the LEC first in the assessment booklet, followed by either the WHOQOL-ID or the WHOQOL-BREF as appropriate. However, although the assessments and associated instructions for completion were ordered thus, some individuals may have addressed the measures (or constituent items) in a different sequence.

Assessment Booklets and Instruction Sheets

In compiling the assessment booklets and the related instruction sheets, some formatting changes were required in order to include the relevant measures and directions in an appropriate manner; a few minor amendments were essential to maximise the compatibility of the WHOQOL-ID and WHOQOL-BREF; and a short new section (four items) on comparative quality of life was introduced.

(i) Front cover:

On the assessment booklet front cover an orientation box (approximately one quarter page size) was included in which participants were: requested to try all the questions; referred to the instructions enclosed on a sheet of coloured paper (pink for the WHOQOL-ID version of the assessment booklet and blue for the WHOQOL-BREF version of the booklet); referred to the postage-paid envelope for return of the completed questionnaire; alerted to the desired 'return by' date; and thanked in advance for their help.

(ii) Instructions:

The instructions for completion of the LEC, the WHOQOL (either ID or BREF) and the related socio-demographic questions and other general items were reproduced as a combined set of instructions for the assessment booklet and included as a single page instruction sheet referred to on the booklet front cover. The instruction sheet was printed on coloured paper so that it would stand out from the other papers included in the study pack to maximise the ease of location by participants.

As the assessment booklets were designed for non-intellectually disabled members of the general public, the augmented response scales were inappropriate and hence the reference to, and illustration of, the 'smiley faces' was removed from the instruction sheet.

Finally, in the section of instructions relating to the WHOQOL, a common response scale (*very unhappy-very happy*) was provided for the common preparatory non-scoring item example on 'support from others' included in both the ID and BREF.

The original response scale for the WHOQOL-BREF non-scoring example (*not at all-completely*) incorporated a fourth scale point descriptor '*a great deal*' which was not included for any subsequent BREF items using the same response scale (for which the fourth point was '*mostly*'). In contrast, the corresponding non-scoring example in the adapted WHOQOL-ID developed in the pilot study, and subsequently used for ID client participants in the main study, had a similar response scale (*not at all-a great deal*) in which '*a great deal*' was the upper scale point anchor. This response scale was used in this same format for subsequent items 3-6. Unfortunately, at the time of initial scale development, the overall project design had not evolved to include the possibility of an ID-BREF comparison within the framework of the main study. Once this was introduced, a pragmatic solution was required in order to provide a consistent approach to achieve comparable non-scoring examples. Therefore, the item content was retained and a different common response scale was selected (reflecting one of the main WHOQOL-ID response scales). As this small change involved a non-scoring item, it was anticipated that this would not impact on participant performance or assessment outcome.

(iii) Socio-demographic questions:

The set of socio-demographic questions included in the section 'About You' at the start of both assessment booklets was that used in the corresponding section of the main study version of the WHOQOL-ID employed with ID clients (and hence consistent across the participant groups). However, immediately following the item seeking information on main occupation/daytime activity (for which eleven possible response categories were provided), an additional item was added requesting details of participants' occupation in 'write-in' free format. This was a back-up item included in case general public participants had difficulty selecting between categories or considered the categories failed to reflect their situation (in the context of self-completed questionnaires, without the benefit of reference to interviewer support and guidance).

(iv) WHOQOL-ID core items:

Minor amendments were made to two items within the core set 1-26: for *item 15* (mobility) the parenthetic interviewer note to record if a walking aid or wheelchair was used for disabled clients was removed; and for *item 17* (activities of daily life) the label of the clarifying statement 'hint' was changed to 'example' as this was more appropriate for general public participants.

(v) WHOQOL-ID supplementary items:

A minor amendment was made to one item in the supplementary module 27-36: for *item 27* (stigmatisation) the clarifying example of possible name calling which referred to ' handicapped, disabled or retarded' (included specifically for the target ID population) was removed, as it was less appropriate for general public participants.

(vi) Response scales:

One descriptor in the response scale which applied to the set of supplementary items (27-36) and one core item (26) was modified, such that the fourth scale point was the same for both the ID and BREF versions of the measure.

As shown in Table 8.47, the third scale point descriptor in the original BREF response scale for item 26 was 'quite often' and the fourth scale descriptor was 'very often'. However, the equivalent fourth scale point descriptor for item 26 in the adapted WHOQOL-ID was 'quite often'.

Table 8.47: WHOQOL-ID and WHOQOL-BREF Response Scales (items 26-36)

Scale	Items	Anchor 1	Intermediate Scale Points 2	3	4	Anchor 5
BREF	26	Never	Seldom	Quite often	Very often	Always
ID	26	Never	Not very often	Sometimes	Quite often	Always
ID	27-36	Never	Not very often	Sometimes	Quite often	Always

As set out in Chapter 5, in the original WHOQOL-BREF, the modifying adjective 'very' was used in connection with both of the upper scale points (at point 5 in two response scales and point 4 in three response scales). As this may have been confusing for ID clients, a consistent approach to all response scales was introduced in the adapted measure by employing 'very' as a modifier for upper scale point 5 only, and introducing 'quite' as a modifier for the intermediate scale point 4. However, once the study design had evolved to include the possibility of an ID-BREF comparison, a consistent set of scale point descriptors was required for item 26. The compromise solution was to use 'often' as the fourth scale point descriptor for both versions of the measure. This was applied to the common set of supplementary items 27-36 also.

(vii) Comparative quality of life and contact with intellectual disabilities:

A set of four new items was introduced (see Part D in the assessment booklets) in which participants were requested to: compare their quality life with that of other people in their neighbourhood; compare their quality of life with that of people with intellectual disabilities; and to indicate the type of contact (if any) they had with an individual with a learning disability e.g. as a family member or friend, in their local community or workplace etc.

This section was added to both versions of the assessment booklet and thus was presented to all general public participants. It was envisaged that these items might add richness and elicit useful comparative data, as well as providing an indication of the extent to which the general public participants had contact with

individuals with intellectual disabilities in their neighbourhood, given that the recruitment of these participants was based on matched residential locality with the group of community clients.

(viii) General items:

Finally, the general question about the method of questionnaire completion (which for the ID clients related to direct client interview or indirect staff proxy interview) was modified to provide options more appropriate for general public participants (postal survey or telephone interview).

Refusal Forms

A refusal form was included in the study pack in an effort to promote active and formal notification of non-consent. The importance of returning the refusal form to signal the declining of participation was outlined in the accompanying letters from the Director of Public Health (A8.28) and the principal researcher (A8.30), as was the availability of the stamped and addressed envelope provided in the study pack for this use. The refusal forms included a footnote reference identifying the version of the assessment booklet presented in the study pack (see A8.32 and A8.33 in Appendix 8), which allowed appropriate data to be gathered in relation to those who formally declined participation, for subsequent use in exploring potential sample bias in terms of participation or refusal by WHOQOL version. However, no other identifiers were applied to the refusal form, and therefore the refusing individual provided all other non-participation data.

8.7 Study Power

The power analysis in relation to potential differences in the quality of life of the three research groups as measured by the WHOQOL-ID was undertaken in two phases: an initial prospective power analysis was undertaken during the early stages of planning the study; but subsequently, this was refined when a clearer picture of the available participant numbers emerged.

Background

Statistical power is defined as the probability of avoiding a Type II error (in which a true research hypothesis is rejected). Acceptable levels of Type I and Type II errors will vary, depending on the nature of the research undertaken. However, by convention α, the probability of Type I error (in which a true null hypothesis is rejected) is set to 0.05; the recommended desirable level of statistical power ($1 - \beta$) is 0.8; and hence β, the probability of Type II error, is 0.2 (Clark-Carter, 1997).

In general, for a given research design and appropriate statistical test, with the probability of Type I error set at an acceptable level, power depends on the number of participants and the anticipated effect size. Therefore, in order to determine the numbers of participants required for a particular study design, likely effect size requires to be considered. Guidance on effect size may be drawn from previous research; likely effect size may be calculated from pilot work employing the same design; or in the absence of either of these methods, researchers may select the effect size they wish to detect, depending on the balance between the relative importance of a Type II error and the potential significance of the research hypothesis.

Effect Size

For the present study, reliable evidence of expected effect size could not be drawn from previous research. Although effect size for the constituent items of the WHOQOL-BREF might have provided a starting point, this instrument was not designed for adults with intellectual disabilities; and the new adapted WHOQOL-ID was being used with this population for the first time. Similarly, effect size could not be calculated reliably from the WHOQOL-ID pilot work undertaken as part of the current research (pilot study two), as this involved very small numbers and employed a different design linked to the development of the measure rather than exploring differences between groups.

In the context of the three research groups, it was anticipated that effect size might vary across the constituent items of the WHOQOL-ID, with a range of small to medium effect size linked with some items, and larger effect size relating to other items. However, it was considered that small-medium effect size might be the smallest that it would be important to detect, as anything smaller would not be of clinical or substantive policy significance.

Participant numbers

As described in Chapter 4, the target number of participants for each of the research groups in the study was driven by the size of the index community group.

Initially the potential maximum size of the community group was the fixed cohort of 180 adults with intellectual disabilities transferred to community care from Hospital A between 1994 and 1999. However, it was anticipated that some individuals from this cohort would no longer be contactable and others might decline to participate in the study. A preliminary analysis undertaken on the basis of approximately 150-160 participants in this group, matched with similar numbers in the comparator hospital and general public groups, suggested that the study would be adequately powered (at 80% or better) for medium and large effect sizes; however, for small effect sizes, study power would be less adequate at approximately 50% (based on a between groups analysis of variance with two degrees of freedom and the probability of Type I error set at 0.05).

However, the addition of a second community cohort of 39 adults with intellectual disabilities transferred to community care from Hospital B during the same five-year period increased the potential maximum size of the community group to 219 individuals, from which it was anticipated that c.200 participants might be recruited. Therefore a further analysis was undertaken on the basis of approximately 200 participants in each of the three groups.

Power Analysis

Statistical power was analysed for the three level between-subjects quasi-experimental design on the basis of a mean group size of 200, using analysis of variance with two degrees of freedom, and with the probability of Type I error (α) set at 0.05. Consultation of appropriate power tables (in Clark-Carter, 1997) indicated that for items on which there was either a *large* effect size ($\eta^2 = 0.138$) or a *medium* effect size ($\eta^2 = 0.059$), the statistical power (1-β, where β is the probability of a Type II error) would be in excess of 0.995; and in the case of any items on which there was a *small* effect size ($\eta^2 = 0.01$) the statistical power would be 0.60. However, since small-medium effect size was selected as the smallest that it would be important to detect, linear interpolation was used to calculate power for a midway effect size, which indicated that for an *intermediate* effect size (set at $\eta^2 = 0.035$), the power would be 0.80.

Thus, in planning the research design, it was concluded that the study would be adequately powered at 80% or better with a mean group size of 200 (or 208 as finally achieved) in the context of the anticipated effect sizes for the main measure used and the desired level of practical significance.

8.8 Summary of Main Study Elements

The design of the study was quasi-experimental, involving a three level between-subjects comparison of the quality of life of 213 adults with intellectual disabilities who were hospital residents, 204 adults with intellectual disabilities who were community clients, and 208 adult members of the general public.

The design required that the three research groups were matched on three key variables: gender (all groups); age (all groups); dependency (hospital residents and community clients); and residential neighbourhood or locality (community clients and general public). Appropriate statistical tests confirmed the adequacy of the match obtained, as no significant differences were found between the groups on these three variables. In addition, although not part of the original design, no significant differences were found between the groups on reported health status, thus there was a fourth serendipitous matching variable.

A subsidiary aspect of the design required that the two general public subgroups were matched on the three key variables of gender, age and residential locality also. Appropriate statistical tests confirmed the adequacy of the match obtained, as no significant differences were found between the subgroups on these three variables.

Overall, 18% of the ID clients participated in the study directly, either individually or with the support of staff; and proxy staff participated on behalf of the remaining 82% of ID clients.

The rate of non-participation within the pools of hospital residents and community clients approached to take part in the study was very low. Therefore detailed analysis of the extent to which the samples were representative or biased was not required. The rate of formal refusal within the pool of potential general public participants was higher (17% overall). Statistical analysis of general public refusers compared with participants indicated there was no significant differences between the groups on the basis of either gender, or the version of the study pack presented; but differences were found on age (refusers tended to be older than participants) and locality (possibly related to the age of participants approached in different localities). However, within the scope of the design (with group matching driven by an index cohort), and given that age-related refusal is not uncommon in survey research, the sample of general public participants was considered to be adequate for the purposes of the study.

Finally, statistical power was calculated in terms of the main experimental measure, the WHOQOL-ID. The design was found to be adequately powered at 80% or better for a three group between subjects comparison in the context of the anticipated effect size and the numbers recruited into each participant group.

8.9 Treatment of Results

In view of the size of the main study, the extent of the related data analysis and discussion of results, and the differing principal and subsidiary aims, the findings are presented in separate chapters as described below.

Assessment Scoring and Study Database

SPSS (Windows) software (Version 10 and subsequently Version 11) was used to collate the participant demographic and assessment data onto a main study database. Similarly, a database was established to collate the data provided by individuals returning formal notification of refusal to participate.

The WHOQOL-ID and WHOQOL-BREF assessments were scored according to the guidance set out for the original WHOQOL-BREF in the Draft WHOQOL User Manual (WHO, 1998).

Related SPSS Syntax provided in the Draft WHOQOL User Manual was customised for the additional ID module items, and the WHOQOL-ID and WHOQOL-BREF item data were checked, recoded as necessary (reversing negatively phrased items), and domain scores were computed. The LEC assessments were scored according to the BILD Life Experiences Checklist Instruction Manual (Ager, 1998); the LEC item data item data were checked; and subscale and total scores were computed. The socio-demographic data and open-ended questions included in the assessment booklets were collated onto the database, in a mixture of numeric coded and string format.

Analysis of the Psychometric Properties of the WHOQOL-ID

A full evaluation of the psychometric properties of the final version of the WHOQOL-ID was carried out in relation to the main study dataset, and the detailed psychometric analysis is presented and discussed in Chapter 9, with supporting tables and figures presented in Appendix 9.

Analysis of Individuals' Quality of Life

A full analysis of the quality of life of the two groups of adults with intellectual disabilities in hospital and community settings was carried out, and the degree of satisfaction reported in relation to the lifestyles and experiences associated with the two forms of supported living was explored. In addition, an analysis of the quality of life of the comparator group of general public adults was carried out, and the quality of life of the 'cared for' adults with intellectual disabilities was compared with that of non-intellectually disabled adults living independently. The detailed quality of life analysis is presented in Chapter 10, with supporting tables presented in Appendix 10.

Chapter 9

Evaluation of the Psychometric Properties of the WHOQOL-ID

The psychometric properties of the scale were examined using the methodology employed by the WHOQOL Group for the original WHOQOL-100 project (see Bullinger et al, 1996; The WHOQOL Group, 1998). This methodology included missing values, response frequency, reliability (internal consistency), and correlation analyses. For the current study, these analyses were carried out at six levels:

1 The total group dataset (N=625) summarising data from hospital residents, community clients and members of the public

2 The three research subgroups: hospital (N=213), community (N=204) and public (N=208)

3 The two versions of the instrument: WHOQOL-ID completed by hospital residents, community clients, plus half of the general public group (combined N=540); and WHOQOL-BREF completed by the other half of the general public group (N=105)

4 A separate analysis of the two versions of the instrument completed by the general public group only WHOQOL-ID (N=103) and WHOQOL-BREF (N=105)

5 According to response mode, summarising data for participants with intellectual disabilities only: direct response (N=74) and proxy response (N=343)

6 At the level of response mode within research subgroup for ID participants: hospital-direct (N=28), community-direct (N=46), hospital-proxy (N=185) and community-proxy (N=158)

These analyses provided information across groups, between groups and within groups, allowing general trends to be examined and potential differences to be identified.

9.1 Missing Values

The rate of missing values within the dataset was very low. For 36 items across 625 subjects, there were only 191 missing values, representing 0.8% of all values. These missing values were examined according to the six levels of analysis and are presented in full in Tables A9.1 – A9.6 in Appendix 9.

Total Group

At this level of analysis, missing values were less than 10% on all items. Overall, 94% of items had less than 2% missing values; and 81% of items had less than 1% missing values. The highest rate of missing values was 7.5% for item 9 (physical environment); and thereafter, the next highest was 2.9% missing values on item 20 (personal relationships).

Research Subgroups (hospital, community and general public)

For the hospital and community groups, there were zero missing values on 32 items (89%) and 28 items (78%) respectively. This contrasted with the data for the general public group, which showed low rates of missing values on all 36 items. It is likely that this finding reflects the impact of a questionnaire administered in interview format for the two groups of ID participants, compared with the postal (and therefore individually completed) format employed in contacting the general public. For both ID client and staff proxy respondents, there was the potential for the interviewer to address minor points of clarification on items, if this was required, and to offer general encouragement to complete the task.

Overall, for the hospital, community and public groups, 97%, 86% and 94% of items had less than 2% missing values respectively. The only items exceeding 5% missing values were item 9 (physical environment) for both the hospital (8.9%) and community (11.8%) groups; item 20 (personal relationships) for the public (6.7%); and item 21 (special relationship/sexual activity) for the public (5.8%).

WHOQOL Version (all subjects)

For the ID and BREF versions of the instrument in relation to the total dataset, 92% and 86% of items had less than 2% missing values respectively. The only items exceeding 5% missing values were item 9 (physical environment) on the WHOQOL-ID (8.5%); and item 21 (sexual activity) on the WHOQOL-BREF (9.5%).

WHOQOL Version (public group)

This level of analysis provided a useful comparison between the two versions of the instrument in relation to one single research subgroup: the general public. On the assumption of group homogeneity (split halves matched for age, gender and residential locality), it was possible that any differences between versions on the non-standard items (facets 1-26) reflected differences between the instruments rather than differences between the groups.

For the ID and BREF versions of the instrument in relation to the public group, 92% and 86% of items had less than 2% missing values respectively also. However, missing values on item 9 (physical environment) were much lower on both versions of the instrument (1%, ID and 2.9%, BREF) for the public group. This finding, together with the findings for the research subgroups suggested that the issues surrounding missing values for item 9 related to the ID client group, rather than the ID version of the instrument.

For the two versions of the WHOQOL used with the public group, the only items exceeding 5% missing values were item 20 (personal relationships) on the WHOQOL-ID (12.6%); and item 21 (sexual activity) on the WHOQOL-BREF (9.5%). These two items were noted from the missing values analysis for the combined general public group also, however, this clarified the linkage between the missing values on these items and the instrument version. All other items, on both versions of the instrument, had less than 3% missing values, despite the postal mode of approach to the public group and the lack of opportunity for interviewer support.

Response Mode (direct and proxy)

This level of analysis provided a comparison between the two response modes applied to one version of the instrument (WHOQOL-ID) in relation to two research subgroups (hospital and community) formed by the ID client participants. On the assumption of subgroup homogeneity (clients of similar age, gender and level of dependency), it was possible that differences between response formats reflected differences in how clients' QOL was perceived and evaluated by clients themselves, and by the staff who know them well and acted as proxies, rather than differences associated with capacity.

Analysis by response mode indicated that for direct and proxy responses 94% and 92% of items had less than 2% missing values respectively, in relation to the data for adults with intellectual disabilities.

Two items had missing values higher than 5% for direct response format: item 9 (physical environment) and item 20 (personal relationships), both with 5.4% missing values. For proxy response format, missing values exceeded 5% on one item only, item 9 (physical environment) with 11.4% missing values. This appeared to suggest that item 9, with missing values noted for the hospital and community subgroups, but not the public, and for the WHOQOL-ID for the total dataset but not the ID version of the instrument used with the public only, may have been more problematic for staff proxies than for ID clients themselves.

Response Mode and Research Subgroup

Further analysis by response mode and research subgroup indicated there were no missing values for the hospital-direct group; and 97% of items had less than 1% missing values for the hospital-proxy group. In the hospital-proxy group, only one item had missing values higher than 5%: item 9 (physical environment) with 10.3% missing values.

In the community-direct and community-proxy groups respectively, 86% and 92% of items had missing values less than 2%. Two items had missing values higher than 5% in the community-direct group: item 9 (physical environment) and item 20 (personal relationships) each with 8.7% missing values. Two items had missing values higher than 5% in the community-proxy group also: these were item 9 (physical environment) and item 11 (body image) with missing values of 12.7% and 5.7% respectively.

The overall response mode analysis showed missing values on item 9 (physical environment) to be double the rate for proxy response mode compared with direct mode. The further breakdown by hospital and community subgroups revealed a slightly different picture for item 9. This item showed missing values ranging from 9-13% across both hospital and community groups and in direct and proxy mode, the only exception being the hospital-direct group. However, the small number of hospital patients (N=28) and community clients (N=46) responding directly, together with the general imbalance of group size for the different response modes prevented any firm conclusion being drawn about the real impact of response mode on missing values for this item.

Summary of Missing Values Analysis

A summary of the key missing values noted across the six levels of analysis is presented in Table 9.1. This shows that four items (9, 11, 20 and 21) had missing values in excess of 5% in one or more levels of analysis. More significantly, two of these items (9 and 20) had missing values higher than 10% (range 10-13%) and one further item (21) approached this criterion (rounded figures). This suggested that items 9, 20 and 21 might have presented problems for the groups or subgroups of participants at the level of analysis noted.

Physical environment (item 9):

This appeared to have presented problems for both ID subjects and their proxies, with missing values noted in all levels of analysis except for the two versions of the instrument with the public group only (level 4). However, the problem appeared to be linked particularly with proxy respondents.

Table 9.1: Summary of Missing Values

Item	Facet	Missing Values > 5%	Missing Values > 10%	Group/Subgroup	Analysis Level	*N*
9	Physical environment	7.5		Total	1	625
		8.9		Hospital	2	213
			11.8	Community	2	204
		8.5		WHOQOL-ID (client/ public)	3	520
		5.4		Direct Response	5	74
			11.4	Proxy Response	5	343
		8.7		Community-Direct	6	46
			10.3	Hospital-Proxy	6	185
			12.7	Community-Proxy	6	158
11	Body image	5.7		Community-Proxy	6	158
20	Personal relationships	6.7		Public	2	208
			12.6	WHOQOL-ID (public)	4	103
		5.4		Direct Response	5	74
		8.7		Community-Direct	6	46
21	Sexual activity	5.8		Public	2	208
		9.5		WHOQOL-BREF (public)	3 / 4	105

The fact that missing values were very low for the WHOQOL-ID (1.0%) and the WHOQOL-BREF (2.9%) when used with the public group suggested that the reworded item 9 was understood adequately by the general population with broadly average intelligence. Therefore, the problem did not seem to be one of intelligibility per se. Although it was possible that some clients responding directly may have had difficulty understanding the item, this did not explain the missing values noted for the staff proxies.

The reworded item 9 included in the WHOQOL-ID *(Do you think this a healthy or an unhealthy area/part of town to live in? For example, thinking about the noise, the traffic, the pollution, the weather etc)* appeared to have adequate semantic equivalence with the original BREF item *(How healthy is your physical environment?)* and, with the use of the illustrative example, also reflected the technical guidance on the meaning of the physical environment facet contained in the Draft WHOQOL User Manual (WHO, 1998).

It was possible that this item had lower salience for ID clients and their proxies compared with other quality of life items, or compared with the general population. However, anecdotal reports of the administration of the WHOQOL-ID suggested that this item presented conceptual problems – particularly for proxies – in terms of the extent to which ID clients might be said to understand, or relate to, the concept of a healthy physical environment.

Although the overall rate of missing values for item 9 was low (<10%) this did raise issues about the performance of proxy respondents on items that were both subjective and reliant on understanding of conceptual meaning.

Personal relationships (item 20):

This appeared to have presented problems for the community group responding directly and those members of the public group who completed the ID version of the WHOQOL. The problems may have reflected poor semantic equivalence with the original BREF item *(How satisfied are you with your personal relationships?)* or may have been linked with the rewording – or the wording specificity - of this item for the WHOQOL-ID *(How happy or unhappy are you with the way you get on with the people you live with?).*

Analysis of the demographic characteristics of the public group who did not complete this item on the ID version suggested indirectly that the majority of these subjects might have been living alone at the time.

The public group participants were not specifically asked to provide information on household numbers, but data were collected on marital status. For the public group overall, 11% were single, 75% were married or living as married and 14% were separated, divorced or widowed. These proportions were reflected similarly for the two different versions of the instrument completed by the public (ID: 12%, 76%, 12%; and BREF: 11%, 73%, 16% respectively). However, 77% of the non-completers of item 20 on the WHOQOL-ID were single, widowed or divorced, compared with only 23% who were married or living as married. On the assumption that the former group may have been living alone, the reworded item 20 would not have been applicable to their situation.

In the case of the small number of non-completers who were married or living as married, as well as the community non-completers (all of whom lived in shared/group accommodation) there may have been reluctance to comment on the extent to which they 'got on' with those they lived with.

It is important to note that the overall rate of missing values on this item was low (<5%), but, despite this, there was some evidence to suggest the need for item revision prior to future use of the instrument.

Sexual activity (item 21):

This appeared to be problematic for those members of the public group who completed the BREF version of the WHOQOL. The re-worded item on the WHOQOL-ID version of the instrument showed much lower missing values (1.9%) compared with BREF (9.5%).

In this case, it was possible that the missing values were linked with the more explicit nature of the BREF item *(How satisfied are you with your sex life?)* compared with the less direct ID item *(Do you have a very close or special relationship with someone?)* with the response options of indicating satisfaction (happiness) with the presence or absence of that relationship.

Analysis of the age structure of the public group overall indicated that 22% of the subjects were less than 40, 54% were between 40 and 60, and 24% were over 60. Similar proportions were represented for the two subgroups of the public completing the two versions of the WHOQOL (ID: 19%, 56%, 25% and BREF: 25%, 52%, 23% respectively). However, 60% of the non-completers of item 21 were over 60; and 80% were over 50. In addition, 90% of these non-completers were female, compared with the public group gender balance of 60% male to 40% female subjects (overall and by version). Finally, only 10% of the non-completers were married compared with 90% who were single, divorced or widowed.

Thus the non-completers were typically older, female and not married. This suggested that the missing values on the explicit BREF item might be accounted for by a combination of factors linked to age, gender and marital status (e.g. 'generational attitudes' to sexuality and the acceptability of reporting on this; reluctance to report sexual relationships existing outside the conventions of marriage; lack of contemporaneous sexual relationships on which to report etc.).

Although the overall rate of missing values for item 21 was low (<5%), this suggested that the explicit nature of the question in the BREF version might be likely to produce higher missing values when used with certain sections of the population. Given the projected demographic trends (an increasingly ageing population, of which the greater proportion will be female), there may be value in reconsideration of this item. This may be an outcome of the work currently underway to develop an older adults version of the WHOQOL, the WHOQOL-OLD (WHOQOL GROUP, in prep.).

Apart from the items discussed above, missing values were very low overall. The guidelines set out by the WHOQOL Group suggest a conservative approach to dealing with low rates of missing values (<10%) by replacement with the series mean. Therefore the subsequent reliability and correlation analyses were conducted on the dataset with missing values replaced.

9.2 Frequencies

Analyses of raw data response frequencies were carried out to examine the distribution of responses across the five point rating scale for each of the 36 WHOQOL items. The frequency analyses carried out in relation to the six levels of analysis are presented in full in Tables A9.7 – A9.12 in Appendix 9.

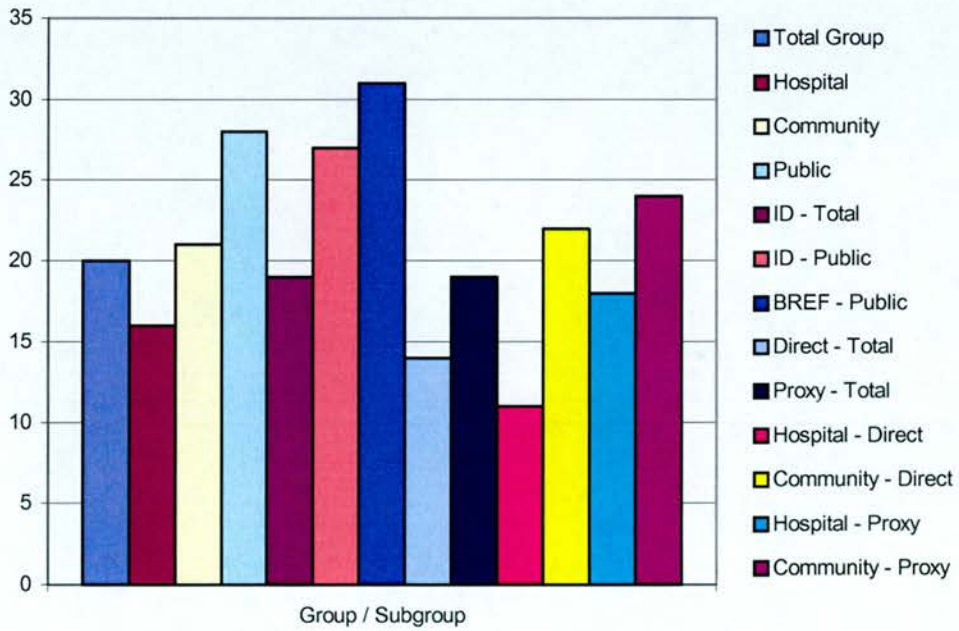
The guidance contained in the Draft WHOQOL User Manual (WHO, 1998) suggests that if items have two or more adjacent scale points accounting for less than 10% of responses, this may indicate frequency problems. This may be indicative of a poor item, failing to discriminate adequately between sections of the target population for the instrument.

In the current study, potential frequency problems (distributions with less than 10% responses on adjacent items) were noted on some items at every level of analysis. However, the achieved frequency distributions require to be approached with caution. For some items, the distribution skew or kurtosis may be an accurate reflection of the situation of patients and clients within the sample (as well cared for and supported in hospital or staffed community homes) rather than a signal of scale problems. For example, it would be expected that such supported living arrangements would provide safe environments (item 8); adequate social support (item 22); and appropriate levels of health and social care (item 24). Similarly, some distributions may be artefacts of the direct versus indirect response modes employed in the study.

Summary of Response Frequencies Analysis

The number of items with poor response frequencies (as defined by <10% on adjacent scale points) varied widely across the groups and subgroups of the six levels of analysis.

Figure 9.1: Number of Items with Poor Response Frequencies by Level of Analysis



As Figure 9.1 shows, the number of items on which poor response frequencies were noted ranged from 11 (31%) for the Hospital-Direct group to 31 (86%) for the BREF-Public group.

For the total group, poor frequency distributions were noted on 20 items.

For the research subgroups, poor frequency distributions were less common for the hospital and community groups (16 and 21 items respectively) than for the general public group (28 items).

Poor frequency distributions for the WHOQOL-ID (completed by all the ID clients and half of the general public group) were noted on 19 items compared with 31 items (the highest rate) for the WHOQOL-BREF (completed by the other half of the general public group).

For the two versions of the instrument in relation to the general public group only, poor response frequency profiles were indicated on 27 items for the WHOQOL-ID, compared with the 31 items for the WHOQOL-BREF.

At the level of response mode analysis, which provided a comparison between the direct and proxy formats applied to one version of the instrument (WHOQOL-ID) in relation to the two research subgroups (hospital and community) formed by the ID participants, poor frequency distributions were evident on 14 items for direct respondents compared with 19 items for proxy respondents.

Further analysis by response mode and research subgroup showed the lowest rate of poor frequency distributions for the hospital-direct group (11 items), compared with the hospital-proxy group (18 items), the community-direct group (22 items) and the community-proxy group (24 items).

Overall, no consistent trend was discernable from the data, but it appeared that the response frequencies for the public showed a higher rate of poor distributions, on both the WHOQOL-ID and the WHOQOL-BREF. Since the psychometric properties of the original BREF version of the instrument have been examined and the instrument found to be valid and reliable (WHOQOL Group, 1998) this finding may be related to the specific characteristics of this particular sample of the general public.

The specific items showing possible frequency distribution problems varied across the different combinations of subject groups and subgroups also, as summarised in Table 9.2. At one or more levels of analysis, possible problems were noted for every WHOQOL item except item 26 (negative feelings).

Table 9.2: Summary of Response Frequencies Analysis

Analysis Level			Total	Research Groups			WHOQOL Version			Response Mode		Response Mode by Research Group			
Domain	Item	Facet		Hospital	Community	Public	ID-520	ID-103	BREF-105	Direct	Proxy	Hospital - Direct	Community-Direct	Hospital-Proxy	Community-Proxy
Gen	1	Overall QOL	X		X	X			X		X		X		X
	2	General health										X			X
Phys	3	Pain ®				X		X	X				X		
	4	Medication ®							X						
	10	Energy							X						
	15	Mobility				X		X	X						
	16	Sleep	X	X	X		X			X			X	X	X
	17	ADL				X		X	X	X		X	X		
	18	Work	X		X	X	X	X	X	X		X	X		X
Psych	5	Positive feelings	X	X	X	X	X	X	X	X			X	X	X
	6	Spirituality		X	X				X		X			X	X
	7	Thinking				X		X	X			X			X
	11	Body image							X						X
	19	Self esteem	X		X	X	X	X	X		X	X	X		X
	26	Negative feelings ®													
Soc	20	Personal relationships	X			X	X	X	X		X		X	X	
	21	Special relationship	X	X	X	X	X	X		X	X	X	X	X	X
	22	Social support	X	X	X	X	X	X	X	X	X	X	X	X	X
Environ	8	Safety	X	X	X	X	X	X	X		X		X	X	X
	9	Physical environment	X		X	X	X	X	X		X				X
	12	Finance		X	X				X		X	X		X	X
	13	Information				X		X	X						
	14	Leisure activities				X		X							
	23	Home	X	X	X	X	X	X	X		X		X	X	X
	24	Health/social care	X	X	X	X	X	X	X	X	X	X	X	X	X
	25	Transport				X		X	X						
DX	27	Stigmatisation ®	X	X	X	X	X	X	X	X	X		X	X	X
	28	Victimisation ®	X	X	X	X	X	X	X	X	X		X	X	X
	29	Ridicule ®	X	X	X	X	X	X	X	X	X		X	X	X
	30	Discrimination ®	X	X	X	X	X	X	X	X	X		X	X	X
	31	Enabling				X		X	X	X			X		
	32	Empowerment	X	X	X	X	X	X	X	X	X	X	X	X	X
	33	Autonomy	X		X	X	X	X	X		X		X		X
	34	Advocacy ®				X		X	X					X	
	35	Respect	X	X	X	X	X	X	X		X		X	X	X
	36	Acceptance	X	X	X	X	X	X	X	X	X	X	X	X	X
			20	16	21	28	19	27	31	14	19	11	22	18	24

X: Denotes items with frequency distributions with <10% on adjacent scale points

For the total group, a number of items demonstrated negative or positive skewness (depending on the direction of item scoring) to the extent that 80% or more responses were distributed between the extreme two points of the 5-point response scale representing high levels of satisfaction with that aspect of quality of life. These items are shown in Table 9.3 below, and summarised by level of analysis in Table A9.13 in Appendix 9.

Table 9.3: Items with Frequency Distributions ≥ 80% at Extreme Scale Points

Domain	Item	Facet	Scale Points	% Responses
General	1	Overall QOL	4 / 5	80
Physical	16	Sleep	4 / 5	80
Social	21	Special relationship / Sexual activity	4 / 5	80
	22	Social support	4 / 5	86
Environment	8	Safety	4 / 5	84
	23	Home	4 / 5	85
	24	Health and social care	4 / 5	85
DX	27	Stigmatisation ®	1 / 2	87
(Hypothesised)	29	Ridicule ®	1 / 2	87
	30	Discrimination	4 / 5	81
	36	Acceptance	4 / 5	86

® Reverse item

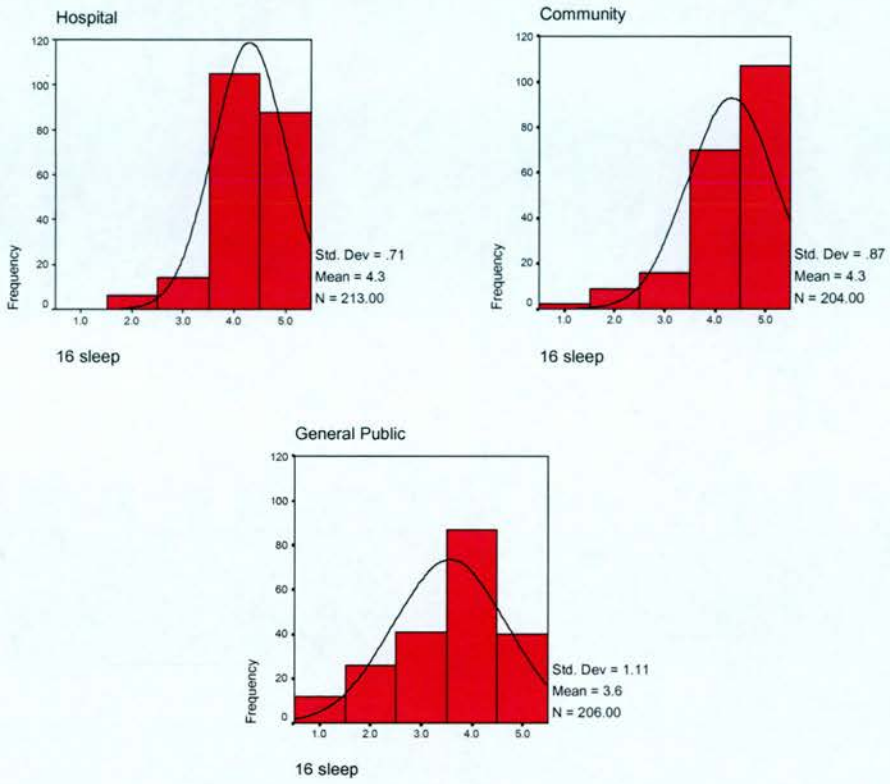
The potential range of issues that may have impacted on the distribution of responses in the present study can be illustrated by further consideration of these items by group and subgroup through the levels of analysis.

Sleep (item 16):

In the total group, 80% of respondents rated their sleep at the upper scale points of 4 or 5 *(ID rating: quite happy/very happy with sleep; BREF rating: satisfied/very satisfied with sleep).* However, as shown in Figure 9.2, the response distribution for the three individual research groups differed considerably, with the general public group being the least skewed, with scale points 4/5 accounting for 62% of responses, compared with 91% for the hospital group and 87% for the community group.

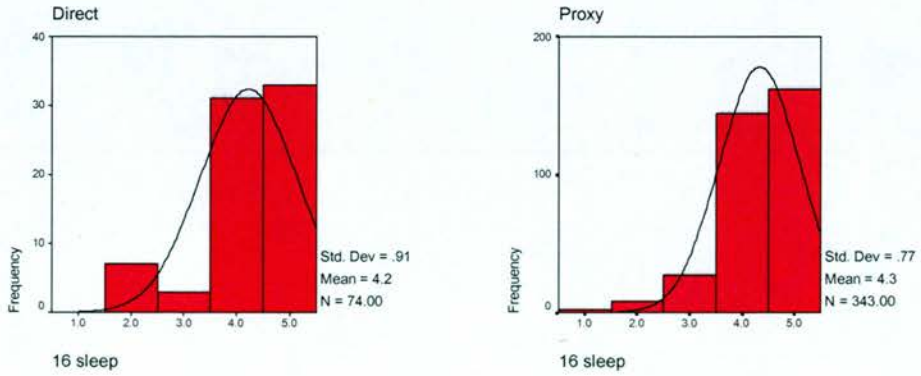
It was possible that the high proportion of proxy staff responding on behalf of clients (86.9% for the hospital group and 77.5% for the community group) tended to make high estimates of satisfaction with sleep in the absence of any contradictory information. This was particularly plausible as the majority of these staff were assigned to daytime shifts.

Figure 9.2: Research Group Frequency Distribution for Sleep (item 16)



However as shown in Figure 9.3, the frequency distributions for direct and proxy responses on this item were similar (87% and 89% respectively), as were the mean scores. (The frequency distributions for the hospital and community groups separately by response mode were similar also: hospital-direct group 86%, hospital proxy group 91%; and community direct and proxy groups both at 87%).

Figure 9.3: Response Mode Frequency Distribution for Sleep (item 16)



Another possibility was that the distribution of responses for ID clients was associated with prescribed medication. Although specific data were not collected on actual use of medication (e.g. hypnotics or other psychotropic drugs), responses to the WHOQOL item on medication (item 4) suggested that two thirds of the clients relied on medication/medical treatments to a moderate or greater extent in order to function in their daily life, compared with only one third of the general public (Table 9.4).

Table 9.4: Research Group Participants Use of Medication/Medical Treatment (item 4)

Research Group	Little or no need for medication/medical treatment		Moderate or greater need for medication/medical treatment	
	N	%	*N*	%
Hospital	70	32.9	143	67.1
Community	66	32.4	138	67.6
General Public	140	68.3	65	31.7

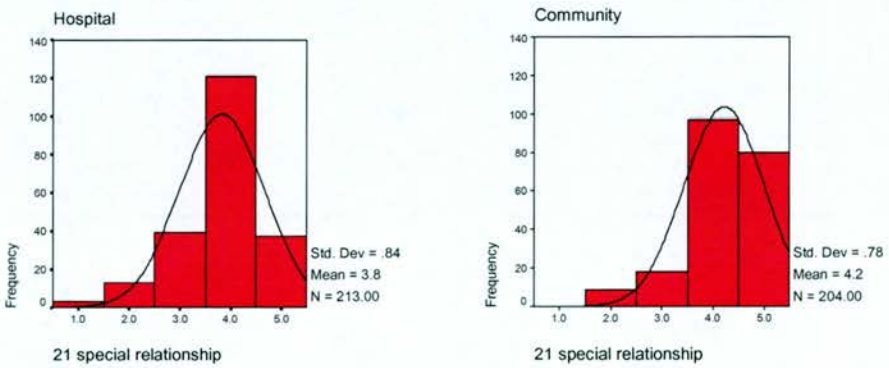
Missing cases: general public group = 3

Special relationship/Sexual activity (item 21):

In the total group, 80% of respondents rated this item on the upper scale points of 4 or 5 *(ID rating: happy/very happy with presence or absence of 'close or special relationship'; BREF rating: satisfied/very satisfied with sex life).* However, as shown in Figures 9.4 and 9.5, the distributions varied across the three research subgroups, and for the two versions of the WHOQOL used with the general public group.

For the hospital group, scale points 4/5 accounted for 74% of the responses compared with 87% for the community group (Figure 9.4).

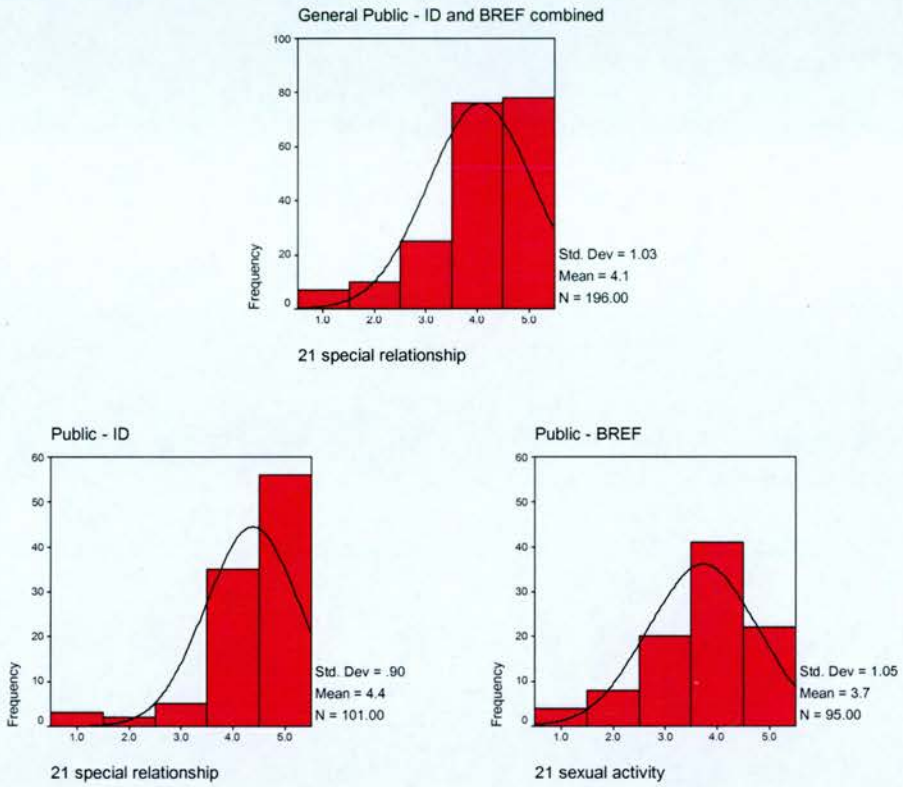
Figure 9.4: Research Group Frequency Distribution for Special Relationship (item 21)



For the combined general public group, scale points 4/5 accounted for 79% of the responses (Figure 9.5).

However, further analysis of the public group revealed markedly different response distributions for the ID and BREF versions of the instrument (in which the wording and response format for item 21 varied). Scale points 4/5 accounted for 90% of responses on the ID version, but only 66% of responses on the BREF.

Figure 9.5: Research Group Frequency Distribution for Sexual Activity (item 21)



It was possible that this difference was associated with some of the issues discussed in connection with the higher proportion of missing values on item 21 noted for the public-BREF compared with the public-ID. Specifically, the less explicit wording of the item on the WHOQOL-ID (in terms of a 'close or special' relationship which may or may not have a sexual component) may have led to a wider and more inclusive item interpretation by some members of the public, such that satisfaction with close platonic friendships, or other close personal relationships (e.g. family) was rated on this item also.

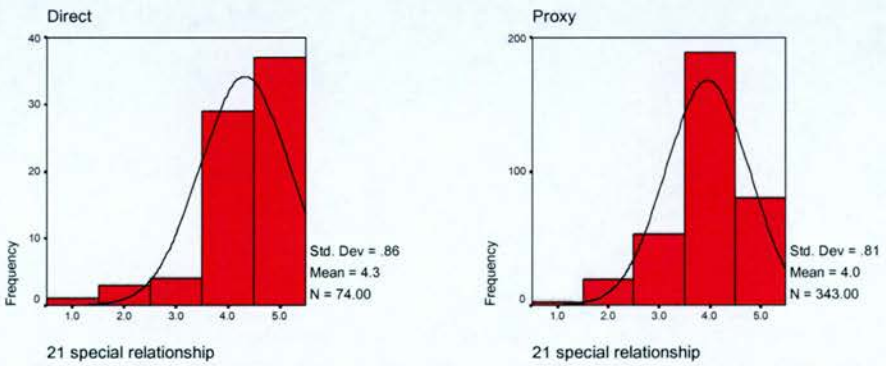
The way in which item 21 may be interpreted to include various kinds of 'friendship' may be relevant to the difference in response distributions noted for the hospital and community groups also. The assessments of hospital residents were carried out during the first year of the resettlement programme. As increasing numbers of hospital residents moved out to new community settings, a number of wards had retracted and closed, and further wards closed during the period of data collection.

In addition, remaining residents were subject to inter-ward moves to make best use of accommodation and promote the most effective case-mix. Clinical and support staff were also moving on at this time, and remaining staff were being re-assigned between wards and teams to re-balance skill mix. Some residents had already lost touch with those they identified as their closest friends (either fellow residents, or in some cases direct care staff) as they had left hospital or moved to a different location on the campus.

In contrast, clients in the community group were established and settled in their new community homes. Although the allocation of residents within hospital wards may be based on a range of factors (most often similarity of care needs), it is seldom approached from the standpoint of friendship patterns. In direct contrast, many of the community home groupings had been formed with the explicit aim of maintaining close and meaningful relationships, wherever possible. Therefore, some of the community group may have re-located with their close relationships intact, others may have had sufficient time to establish satisfying close relationships within the project setting, in day service settings, or within the local neighbourhood.

Differences were noted between the response distributions for direct and proxy groups also. As shown in Figure 9.6, scale points 4/5 accounted for 89% of responses in the direct group compared with 78% in the proxy group. This suggested that clients who were able to express themselves directly indicated more satisfaction with their close or special relationships, compared with the indirect ratings of staff proxies.

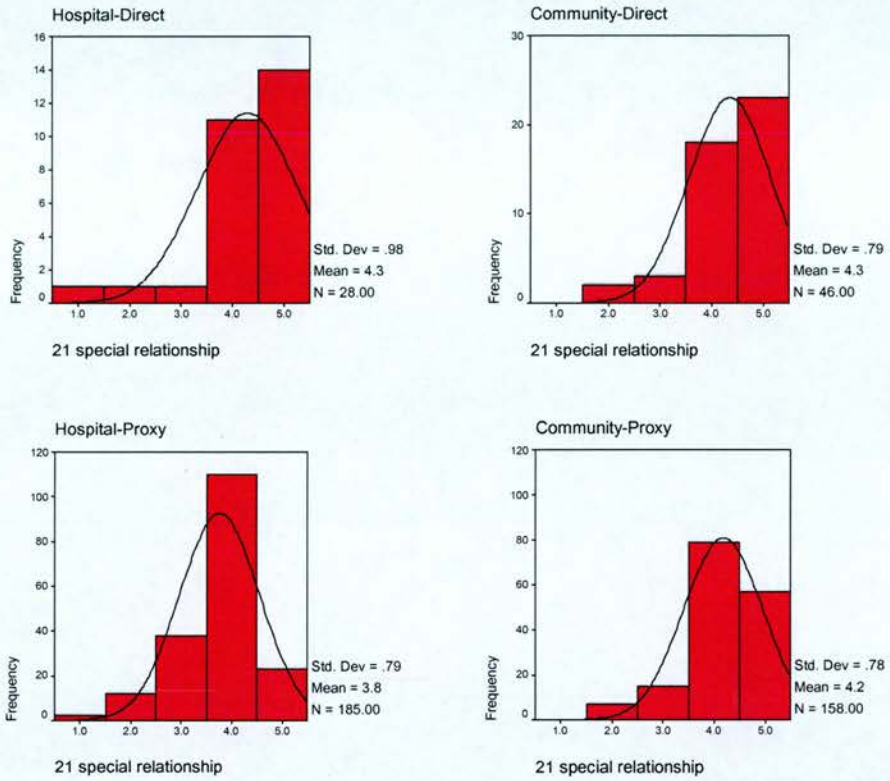
Figure 9.6: Response Mode Frequency Distribution for Special Relationship (item 21)



This may have related to the higher dependency of those patients and clients for whom proxy assessments were required (as a result of the absence of capacity, or the presence of major communication difficulties) and the impact of this on their personal relationships; or it may have related to the process of proxy judgements and/or their reliability.

Further analysis by client group and response mode indicated that although scale points 4/5 accounted for 89% of responses for both the hospital-direct and community-direct groups, the proxy responses on points 4/5 differed considerably, with 72% for the hospital-proxy group compared with 86% for the community-proxy group (Figure 9.7).

Figure 9.7: Research Group and Response Mode Frequency Distribution for Special Relationship (item 21)



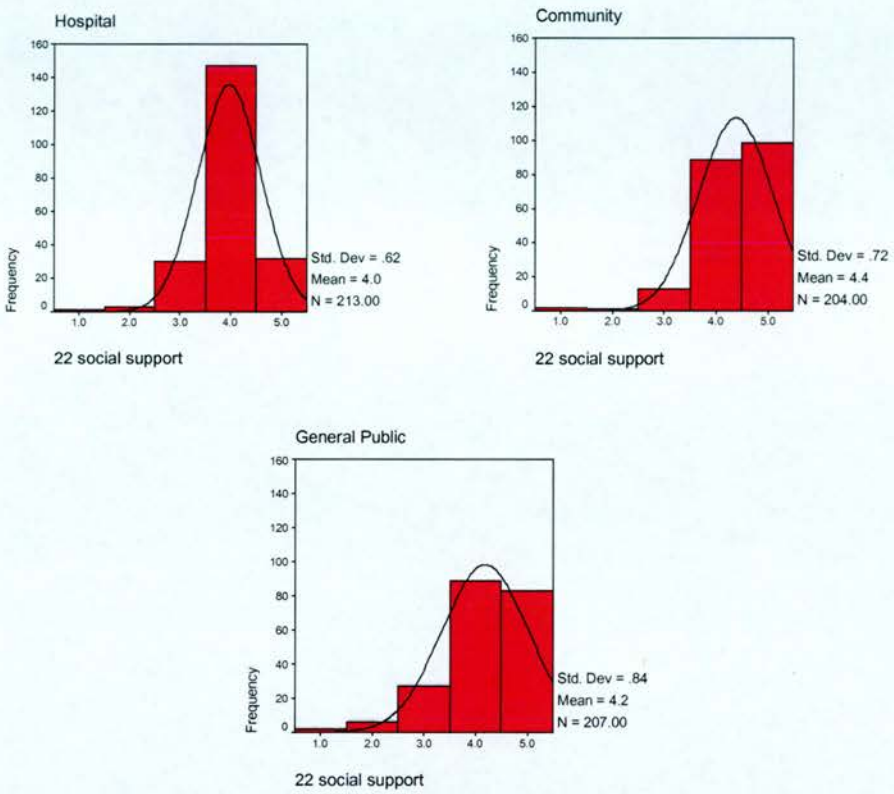
This suggested that in community settings, clients and staff proxies were making similar judgements on this item, whereas in hospital settings there was greater disparity between direct and indirect respondents. This may have related to a greater social distance between residents and hospital staff (in terms of professional boundaries and as an artefact of less permanent shift assignments) compared with the more cohesive social unity of clients and staff in a community group home.

Social support (item 22):

In the total group, 86% of respondents rated their social support at the upper scale points 4 or 5 *(ID rating: quite happy/very happy with support from friends; BREF rating: satisfied/very satisfied with support from friends).* The response distributions for the three research groups are shown in Figure 9.8.

The community group showed the greatest degree of negative skew, with 92% of responses at scale points 4/5 compared with 84% for the hospital group and 83% for the general public.

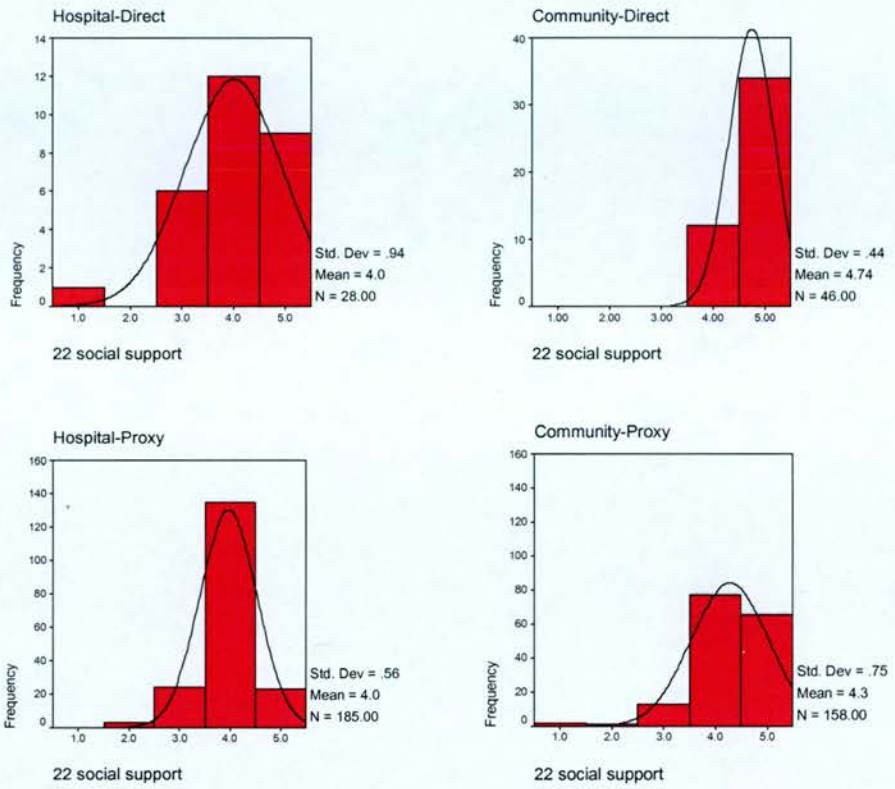
Figure 9.8: Research Group Frequency Distribution for Social Support (item 22)



The proportions of responses in the two response modes were similar, with 91% of direct respondents and 88% of proxy respondents at scale points 4/5. However, further analysis by response mode and research group indicated that, although both hospital and community groups benefited from high levels of social support, there were differences between the subgroups with scale points 4/5 accounting for 75% of responses for the hospital-direct group, 100% for the community direct group, 85% for the hospital-proxy group and 90% for the community-proxy group.

The high levels of social support indicated for the community group (in both direct and proxy mode) may have reflected the degree of customisation to individual need involved in purpose-designed community projects. The finding for the hospital group may have reflected the 'built-in' support that comes from group living within the environment of a campus institution also. However, the variation in response distribution for the two direct clients groups was particularly relevant in the context of the current study, with a 25% difference in the numbers of clients rating at the upper two scale points on this item.

Figure 9.9: Research Group and Response Mode Frequency Distribution for Social Support (item 22)



Safety (item 8):

In the total group, 84% of respondents rated their safety at the upper two scale points of 4 or 5. *(ID rating: feeling quite safe/very safe in daily life; BREF rating: feeling very much/extremely safe in daily life).* A similar high level of positive response at scale points 4/5 was reflected in the hospital, community and general public groups (83%, 84% and 85% respectively) and for the direct and proxy response modes (81% and 84% respectively).

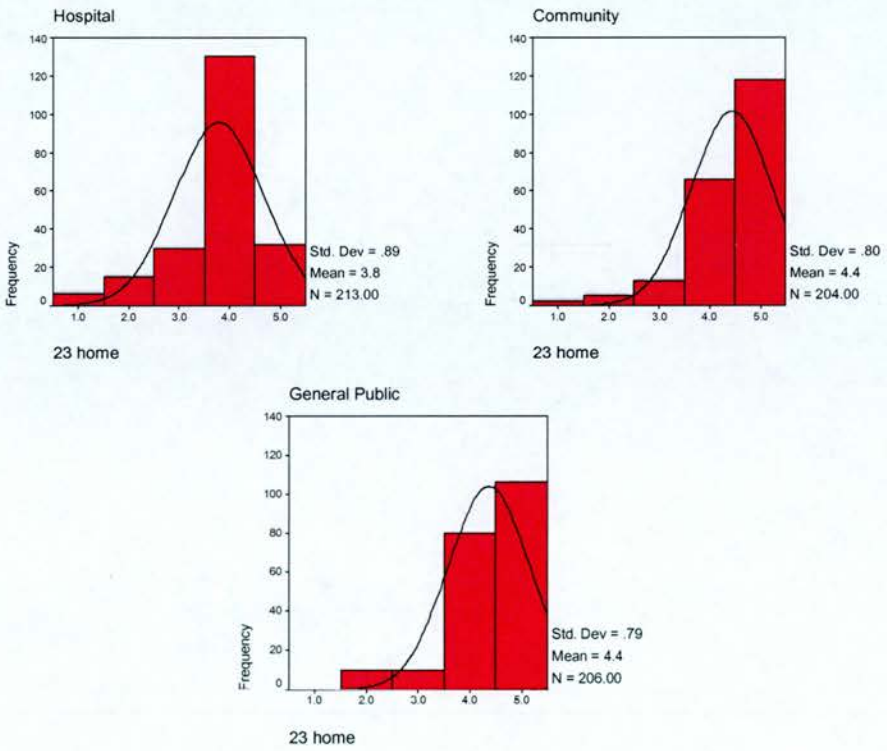
This finding may reflect an extension of some of the issues as discussed for social support. The hospital and community clients all lived within a context of 24-hour staff support. Within the segregated hospital campus, an explicit range of measures existed to promote physical safety and security (e.g. locked doors, vehicle speed restrictions, staff vetting). In the community houses, safety may be seen as implicit in the staffing arrangements for clients both within the home and being accompanied within the local community. Furthermore, one of the principles underpinning the community care strategy was that community homes should be established in neighbourhoods that were not exposed to undue risk (i.e. not making use of vacant accommodation in socially deprived or so-called 'priority' areas). Therefore, the homes were dispersed in a range of localities

reflecting the broad demographic mix of a relatively prosperous geographical region. As the general public group lived in the same areas (based on the group matching process) they may be seen as benefiting from the same degree of safety and security provided by these neighbourhoods.

Home (item 23):

In the total group, 85% of respondents rated their home at the upper scale points of 4 or 5 *(ID rating: quite happy/very happy with place live in; BREF rating: satisfied/very satisfied with conditions of living place).* However, as shown in Figure 9.10 the response distribution for the three research groups differed with the hospital group being the least skewed, with scale points 4/5 accounting for 76% of responses, compared with 90% for both the community and general public group. The high level of positive response for the community and general public groups may have been linked to some of the issues discussed for safety (above). In addition, there may have been a 'halo' effect (Asch, 1946) for the community clients, all of whom had been former hospital residents.

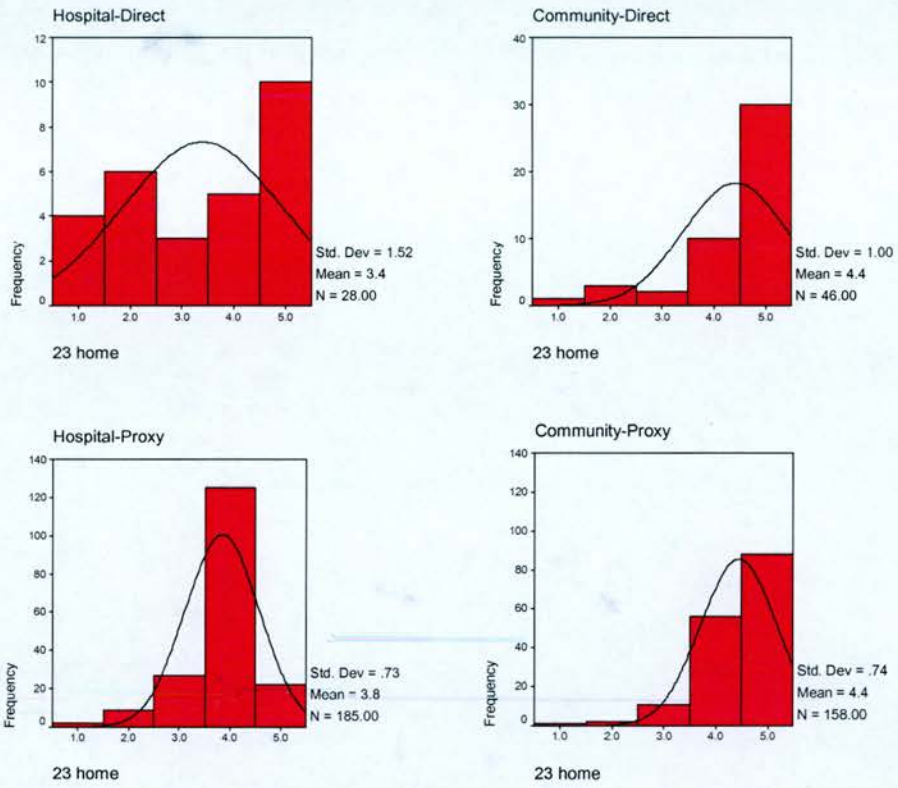
Figure 9.10: Research Group Frequency Distribution for Home (item 23)



For the hospital group, the relatively lower mean score and the closer approximation to a normal distribution may have reflected the differential values attached to an institutional home (e.g. shared with many people, fewer opportunities for privacy, regime dictated by needs of larger group) irrespective of the provision of a secure environment and basic amenities.

Further analysis of the research groups by response mode indicated that scale points 4/5 accounted for similar response levels for the community group in both direct and proxy format (87% and 91% respectively). However, as Figure 9.11 shows, only 54% of the hospital-direct group responded at scale points 4/5 compared with 80% for the hospital-proxy group.

Figure 9.11: Research Group and Response Mode Frequency Distribution for Home (item 23)



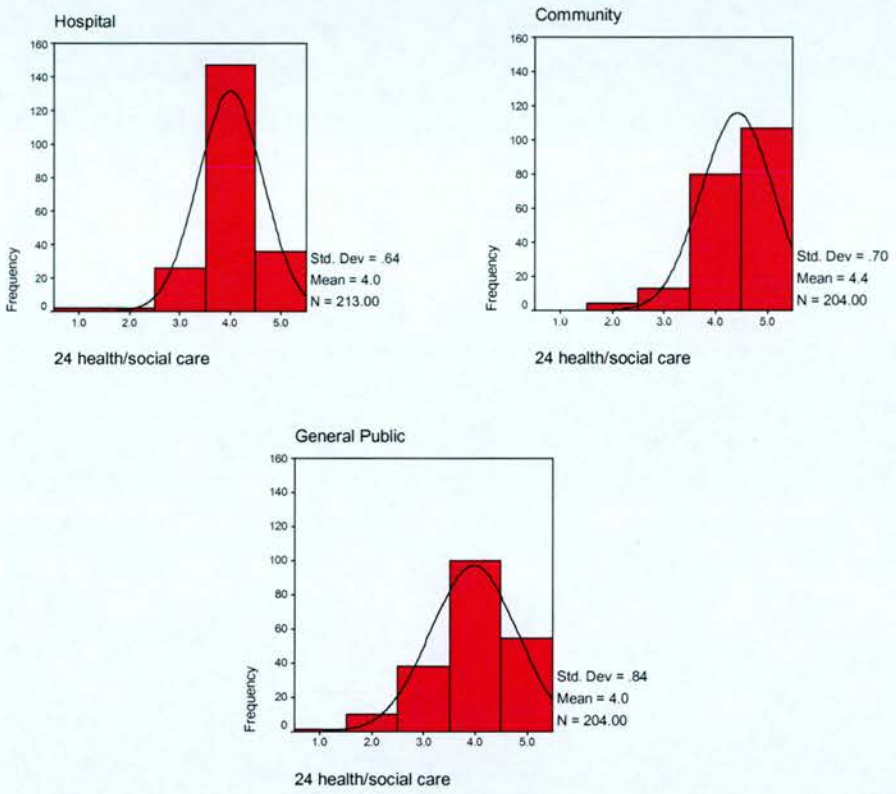
Caution should be exercised in interpreting this finding, in view of the small numbers in the hospital-direct group. However, hospital residents' subjective experience of their living place (as expressed directly) appeared to be considerably poorer than that of their care staff. Hospital staff acting as proxies were requested to respond from the standpoint of the client they represented, but they may have been subject to a range of external influences on this item also (e.g. subtle hierarchical or institutional pressures, personal attitudes, cognitive dissonance).

Health/Social care (item 24):

In the total group, 85% of respondents rated their health/social care at the upper scale points of 4 or 5 *(ID rating: quite happy/very happy with health services available; BREF rating: satisfied/very satisfied with access to health services).*

However, as shown in Figure 9.12, the response distribution for the three individual research groups differed considerably, with the general public group being the least skewed, with scale points 4/5 accounting for 76% of responses, compared with 86% for the hospital group and 92% for the community group.

Figure 9.12: Research Group Frequency Distribution for Health/Social Care (item 24)



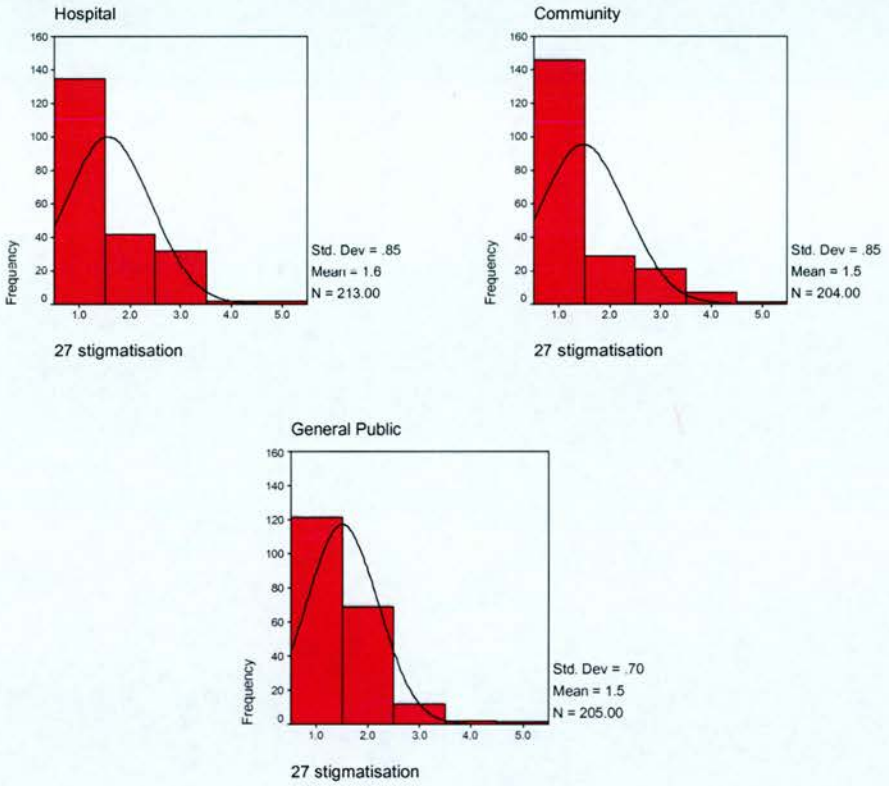
Analysis of the general public group by WHOQOL version indicated exactly the same level of responses at scale points 4/5 for both the ID and the BREF versions of the instrument (76%). This tended to suggest relatively high levels of satisfaction with availability of, and access to, local health services within the geographical area.

It was unsurprising that the hospital and community groups responded positively at higher levels, as the staffed environments in which they lived (whether health or social care based) promoted and supported ongoing health surveillance, prompt health treatment and compliance with health care regimes. In addition, some characteristics of clients linked to their intellectual disabilities (e.g. acquiescence) may have moderated judgements in relation to their perceived carers. Further analysis indicated similarly high responses at scale points 4/5 for both direct and proxy response mode overall, and within the two response modes for the hospital and community groups separately.

Stigmatisation (item 27):

In the total group, 87% of respondents rated stigmatisation at the lower scale points 1 or 2 *(ID and BREF rating: never/not often called names or things that don't like).* The response distributions for the three research groups are shown in Figure 9.13.

Figure 9.13: Research Group Frequency Distribution for Stigmatisation (item 27)

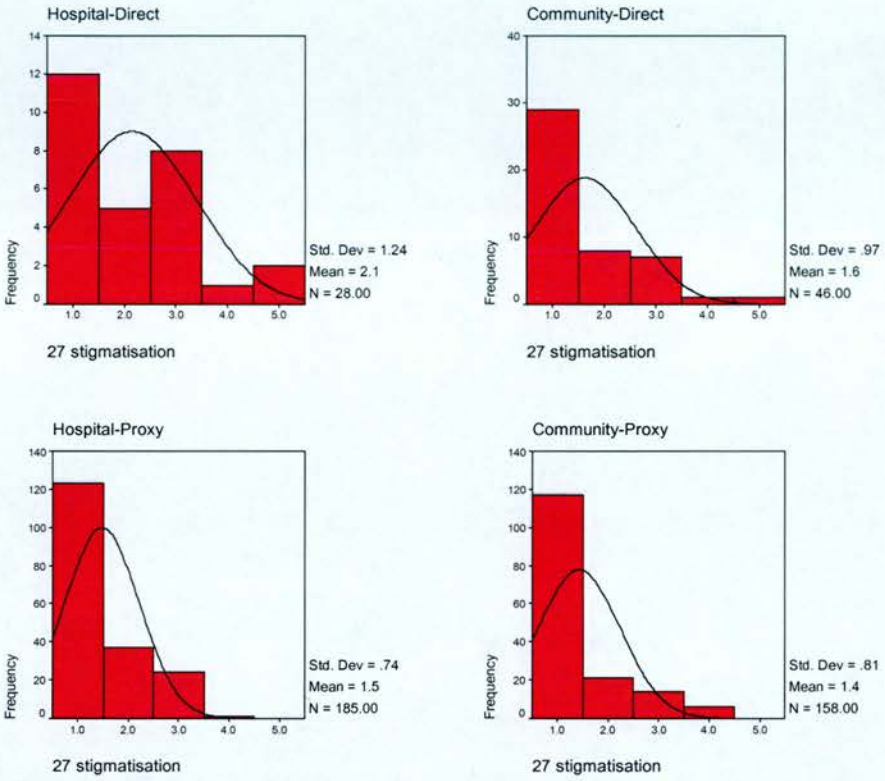


The general public group showed the greatest degree of positive skew, with 93% of responses at scale points 1/2 compared with 83% for the hospital group and 86% for the community group. This suggested that stigmatisation was not prevalent in the environments in which all three groups resided. Many of the issues discussed in relation to social support, home and safety (safe environments, high levels social support, staff support for clients) may have been relevant to the response distribution on this item.

However, the low levels of stigmatisation for both hospital and community groups overall masked a different pattern of responding that emerged from the analysis of the two ID client groups by response mode. As shown in Figure 9.14, scale points 1/2 accounted for similar response levels for the community group in both direct and proxy format (80% and 87% respectively), however, only 61%

of the hospital-direct group responded at scale points 1/2 compared with 87% for the hospital-proxy group.

Figure 9.14: Research Group and Response Mode Frequency Distribution for Stigmatisation (item 27)

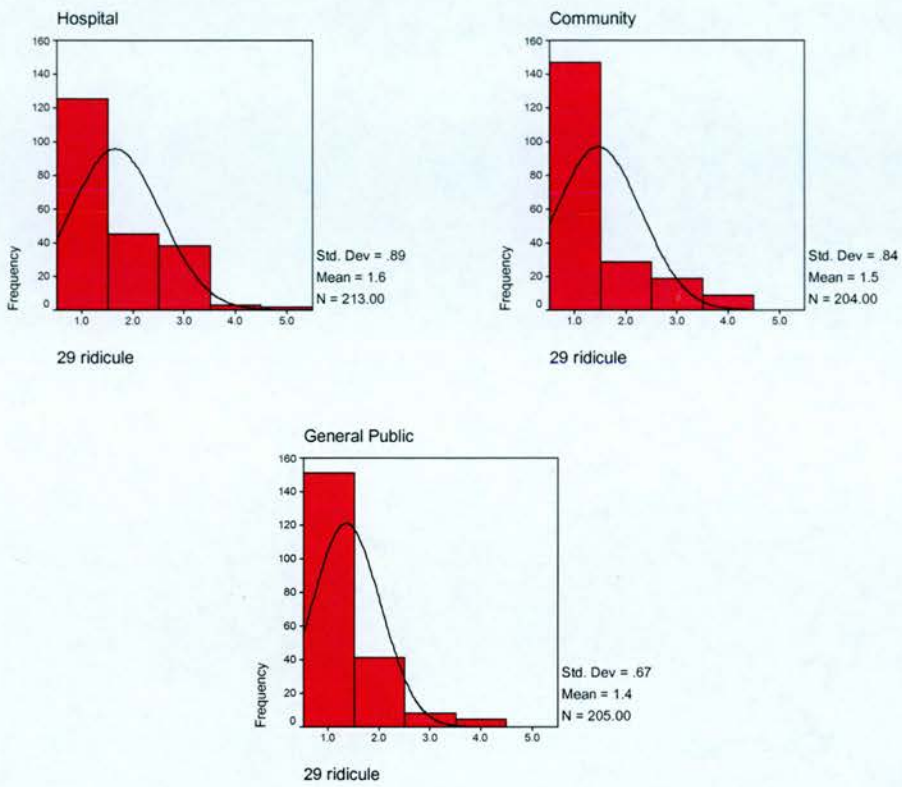


Once again, caution was needed in interpreting this finding, in view of the small numbers in the hospital-direct group. However, hospital residents' subjective experience of stigmatisation (as expressed directly) appeared to be greater than that of their care staff. Hospital staff may have been subject to a similar range of influences on this item as discussed in relation to item 23 (home). Proxy staff responses at scale points 1/2 were at the same level for both hospital and community groups (87%), but since community clients responding directly at this level was of a similar order (80%) it seemed that the experience of stigmatisation in the range of community settings was less common for these clients.

Ridicule (item 29):

In the total group, 87% of respondents rated ridicule at the lower scale points 1 or 2 *(ID and BREF rating: never/not often teased or made fun of because of who you are).* The response distributions for the three research groups are shown in Figure 9.15.

Figure 9.15: Research Group Frequency Distribution for Ridicule (item 29)

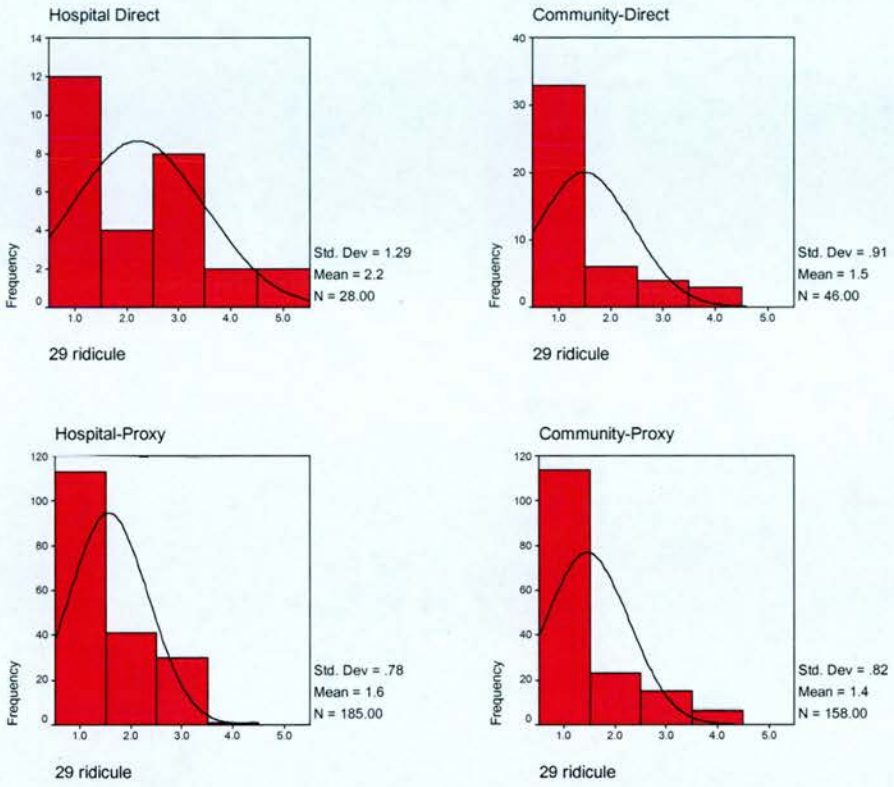


The general public group showed the greatest degree of positive skew, with 94% of responses at scale points 1/2 compared with 79% for the hospital group and 86% for the community group. This suggested that like stigmatisation, ridicule was not prevalent in the environments in which all three groups resided.

However, once again, a different pattern of responding emerged from the analysis of the two ID client groups by response mode. As shown in Figure 9.16, scale points 1/2 accounted for similar response levels for the community group in both direct and proxy format (85% and 87% respectively), however, only 57% of the hospital-direct group responded at scale points 1/2 compared with 83% for the hospital-proxy group.

Taking into account the need for cautious interpretation, it would appear that hospital residents' subjective experience of ridicule (as expressed directly) was greater than that of their care staff. Hospital staff may have been subject to a similar range of influences on this item as discussed in relation to item 23 (home) and item 27 (stigmatisation). Proxy staff responses at scale points 1/2 were similar for both hospital and community groups (83% and 87% respectively), but since the proportion of community clients responding directly at this level was similar (85%) it appeared that the experience of ridicule was less common for these clients in the community settings.

Figure 9.16: Research Group and Response Mode Frequency Distribution for Ridicule (item 29)



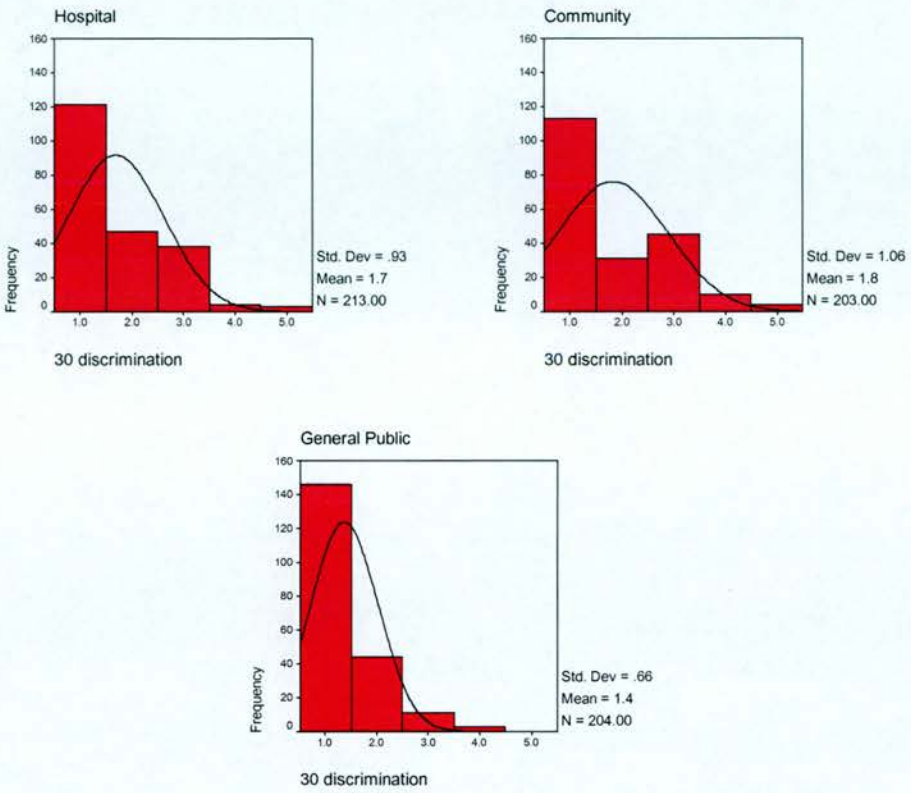
Discrimination (item 30):

In the total group, 81% of respondents rated discrimination at the lower scale points 1 or 2 *(ID and BREF rating: never/not often feel that some people discriminate against or treat differently from others).* The response distributions for the three research groups are shown in Figure 9.17.

The general public group showed the greatest degree of positive skew, with 93% of responses at scale points 1/2 compared with 79% for the hospital group and 71% for the community group. This suggested that although discrimination was not prevalent in the environments in which all three groups resided, it was more commonly experienced by the two client groups than by the general public, despite the community clients residing in similar neighbourhoods to the public group.

However, the distribution of responses that emerged from analysis of the two ID client groups by response mode suggested a more complex picture.

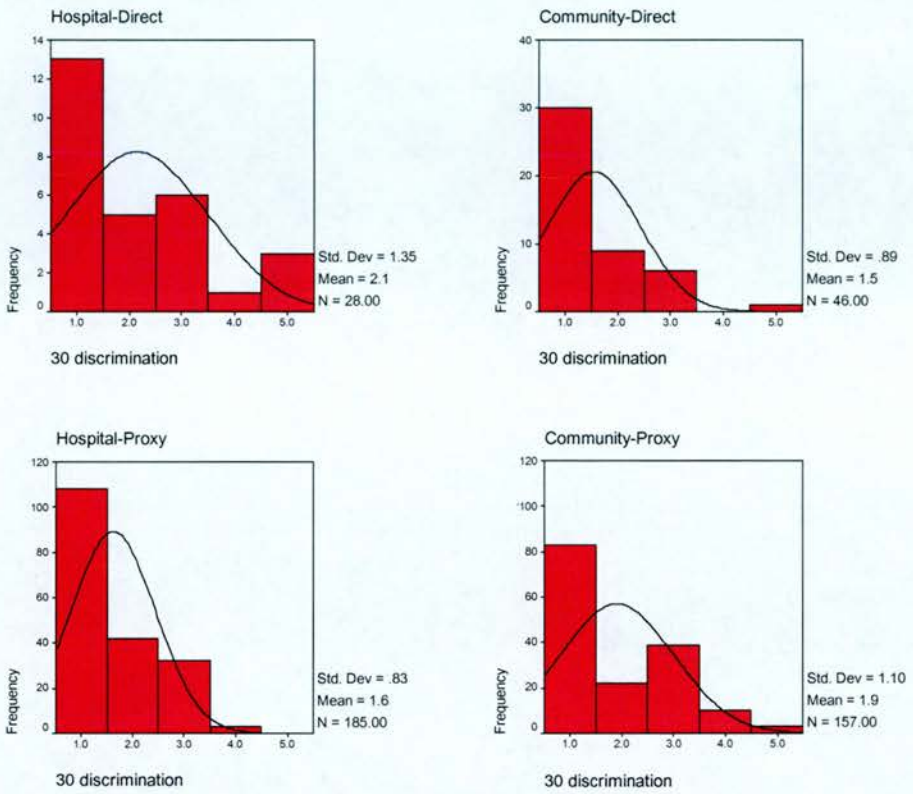
Figure 9.17: Research Group Frequency Distribution for Discrimination (item 30)



As shown in Figure 9.18, scale points 1/2 accounted for very different response levels for the two groups in both direct and proxy formats. In this case the trend for lower proxy ratings compared with direct client ratings was evident in the hospital group, but was reversed for the community group: 64% of the hospital-direct group responded at scale points 1/2 compared with 81% of the hospital-proxy group; however, 85% of the community-direct group responded at scale points 1/2 compared with only 67% for the community proxy group.

Once again, caution was required in view of the small numbers in both the hospital and community direct groups. It appeared that hospital residents who were able to express their views directly reported relatively low levels of discrimination, but not as low as the reports of proxy staff suggested might be in evidence. In contrast, community clients expressed little or no experience of discrimination, which may be evidence of their perception of a more benign community environment compared with hospital settings (since all the clients in the community group were former hospital residents). However, the community staff proxies reported discrimination at levels similar to that of the hospital-direct group. This may have related to aspects of the levels of dependency of community clients for whom proxy assessments were required.

Figure 9.18: Research Group and Response Mode Frequency Distribution for Discrimination (item 30)



As shown in Table 9.5, two thirds of clients for whom proxy assessments were conducted had high levels of dependency. Many of those with high dependency had specific syndromes or associated physical disabilities, features of which would be evident to an ordinary observer (e.g. facial features associated with Down's syndrome, lack of muscular co-ordination associated with cerebral palsy, wheelchair use etc). Such characteristics may have been associated with actual discrimination in the community settings (e.g. Flynn, 1989); alternatively, community staff proxies may have been making downward social comparisons (Festinger, 1954) that influenced their proxy judgements.

Table 9.5: Level of Dependency of Hospital and Community Groups by Response Mode

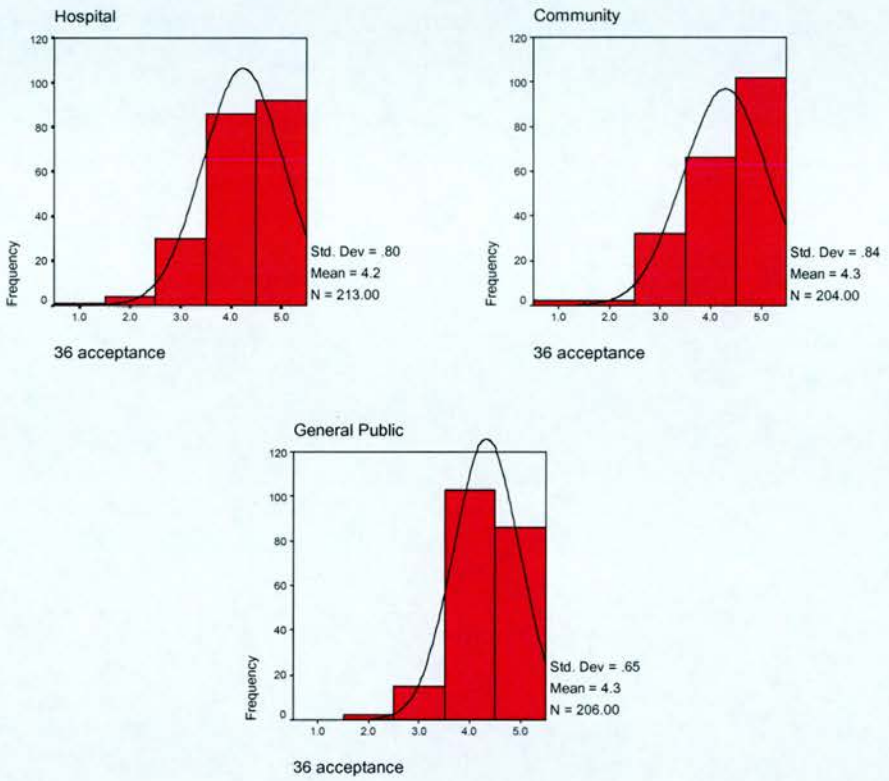
Dependency	Hospital		Community	
Level	Direct	Proxy	Direct	Proxy
Low-Medium	85.7	34.1	86.0	35.2
High	14.3	65.9	14.0	64.7

Missing cases: community-direct group = 3, community-proxy group = 2

Acceptance (item 36):

In the total group, 86% of respondents rated acceptance at the upper scale points 4 or 5 *(ID and BREF rating: often/always feel accepted by others).* The response distributions for the three research groups are shown in Figure 9.19.

Figure 9.19: Research Group Frequency Distribution for Acceptance (item 36)

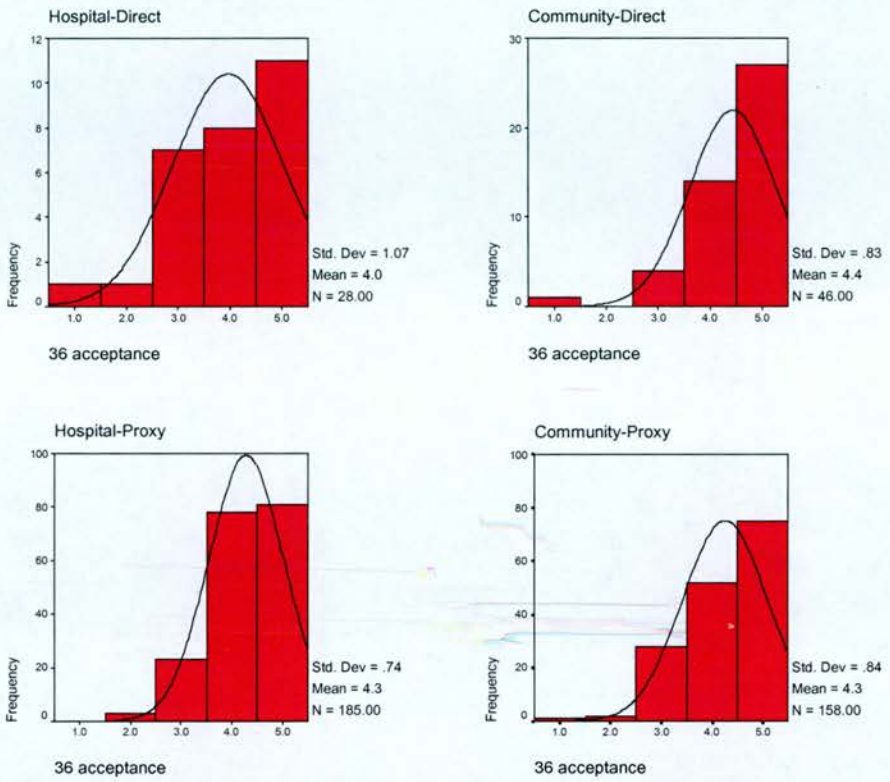


The general public group showed the greatest degree of negative skew, with 92% of responses at scale points 4/5 compared with 84% for the hospital group and 82% for the community group. This suggested that all three research groups experienced high levels of social acceptance.

However, the high levels of social acceptance for both hospital and community groups overall masked a different pattern of responding that emerged from the analysis of the two ID client groups by response mode. As shown in Figure 9.20, scale points 4/5 accounted for similar response levels for the community group in both direct and proxy format (89% and 80% respectively), however, only 68% of the hospital-direct group responded at scale points 4/5 compared with 86% for the hospital-proxy group.

It appeared that hospital clients who were able to express their views directly reported relatively high levels of acceptance, but not as high as the reports of proxy staff suggested might be in evidence.

Figure 9.20: Research Group and Response Mode Frequency Distribution for Acceptance (item 36)



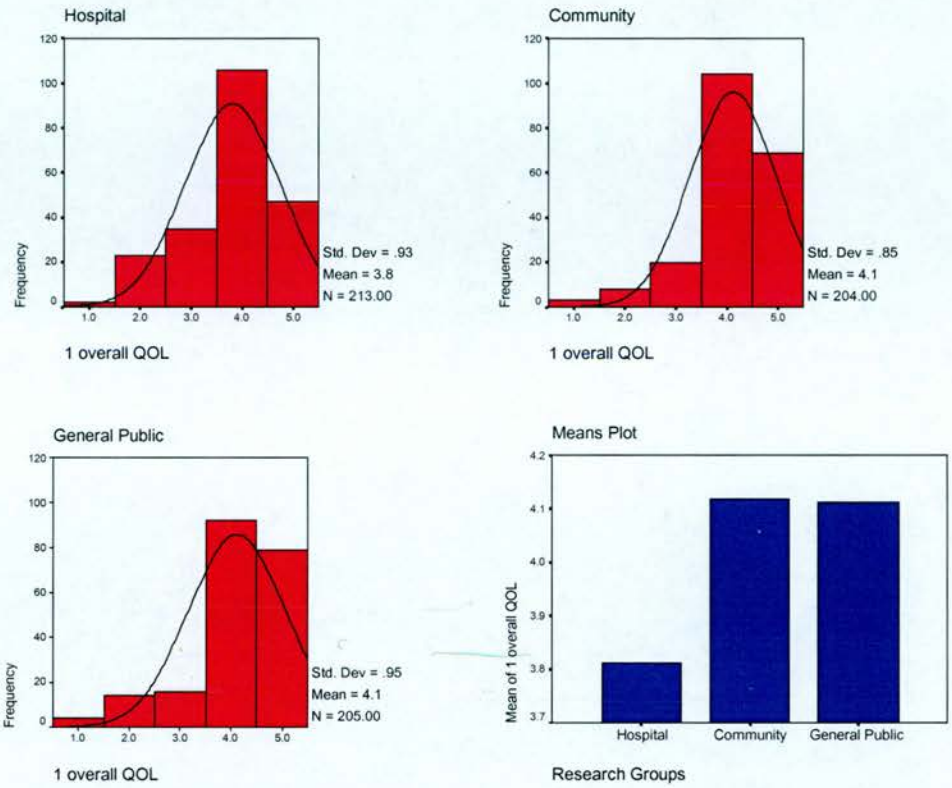
Proxy staff responses at scale points 4/5 were at similar levels for both hospital and community groups, but since community clients direct responses were at a similar level, it appeared that the experience of acceptance was more common for these clients in the community settings. Once again, the issues in relation to social support and home (high levels of social support, staff support for clients) may have been relevant to the response distribution on this item.

Overall Quality of Life (item 1):

For the total group, 80% of respondents rated their quality of life at the upper scale points of 4 or 5 *(ID rating: quite happy/very happy with life; BREF rating: QOL good/very good).* For the hospital group, scale points 4/5 accounted for only 72% of responses, compared with 85% for the community group and 83% for the public.

As shown in Figure 9.21, the overall shape of the response frequency distribution also varied between the three groups. One-way analysis of variance confirmed a difference between the means ($F_{2, 619} = 7.728$, $p<0.001$), with the associated means plot confirming hospital residents relatively lower mean quality of life on this global item.

Figure 9.21: Research Group Frequency Distribution for Overall Quality of Life (item 1)

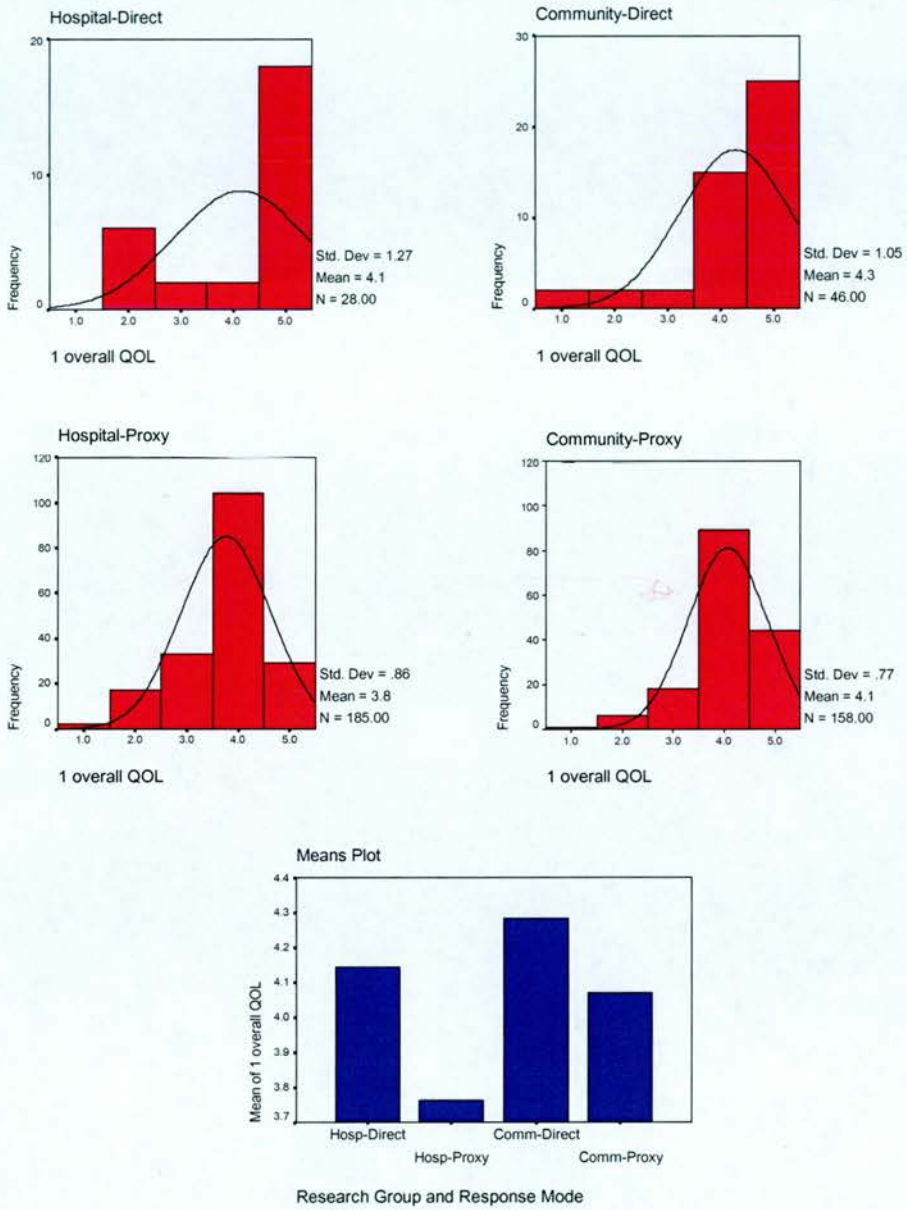


As shown in Figure 9.22, this pattern was also evident in the analysis of the three groups according to response mode ($F_{3, 413} = 6.305$, $p<0.001$) with the lowest mean for the hospital-proxy subgroup. As the numbers between the groups were not equal, Welch's statistic was applied to confirm this significant difference ($p = 0.001$).

This suggested that the lower mean frequency scores may have been associated with the assessments of proxy respondents (direct care staff); and the difference between the overall mean scores of ID clients responding directly (hospital and community groups combined), compared with those for whom indirect responses were recorded via proxies, was found to be significant also ($t = 2.348$, $df = 91.074$, $p = 0.021$, 2-tailed, variances unequal).

This may have related to the higher dependency of those patients and clients for whom proxy assessments were required (as a result of the absence of capacity, or the presence of major communication difficulties) and the impact of this on their *actual* quality of life; or it may have reflected aspects of the process of proxy judgements and/or their reliability.

Figure 9.22: Research Group and Response Mode Frequency Distribution for Overall Quality of Life (item 1)



However, the overall shape of the response frequency distribution for this item reflecting apparent satisfaction with quality of life for all three groups required to be interpreted with caution, as low expectations and adaptation (Felce and Perry, 1997) may have influenced judgements for the two ID client groups.

For the general public group, the geographical context of a city providing high quality of life relative to other UK locations may have been an issue also, particularly in comparison with the diverse range of geographical, political,

industrial, economic and social conditions reflected in the original 15 field trial centres from which the WHOQOL project pilot data was collected (WHOQOL Group, 1998).

Table 9.6: Health Status of Research Group Participants

Research Group	Ill		Not Ill	
	N	%	*N*	%
Hospital	31	14.6	182	85.4
Community	42	20.6	162	79.4
General Public	33	16.2	171	82.2
Total Group	106	17.0	515	82.9

Missing cases: general public group = 4

Finally, it should be noted that the WHOQOL pilot data were collected from similar numbers of individuals who were both ill and well (WHOQOL Group, 1998b). However, as Table 9.6 shows, 83% of the participants in the current study rated themselves as 'not ill'.

9.3 Reliability

The reliability of the adapted WHOQOL-ID was examined using Cronbach alpha. This measure of reliability examines the internal consistency among items within a summated scale. Alpha values of 0.7 or higher are regarded as indicating an acceptable level of internal consistency; and alpha values of 0.6 or higher are considered satisfactory within the context of exploratory studies (Hair et al, 1998).

Corrected item-total correlations (the correlation of each item to the summated scale score calculated without the contribution of that item) were scrutinised also. A scale with good internal consistency might be expected to demonstrate item-total correlations of 0.4 or above. For the purposes of the present study, the threshold of minimum acceptable level of internal consistency was set at 0.3; and item-total correlations below the threshold of 0.25 were noted as indicative of possible problems with an item (Kline, 1993).

As the missing values analysis had indicated that the criterion for replacement of missing values was met (missing values <10%), the reliability analysis was conducted with missing values replaced by the series mean.

The reliability analysis was conducted in three stages:

> *Stage One:* Analysis of the original four WHOQOL-BREF base domains (physical, psychological, social and environment) and the additional hypothesised (ID) domain DX

Stage Two: Analysis of the reliability of domain DX with selected item variations

Stage Three: Analysis of the reliability of domain DX with selected item and sub domain structure variations

9.3.1 WHOQOL Base Domains and DX

A reliability summary for the four original WHOQOL domains and the additional hypothesised domain (DX) is presented in Table 9.7. Alpha values, item-total correlations reaching 0.3 or higher (Pearson *r*), and possible problem items are identified for the research groups and subgroups at the various levels of analysis.

Total Group

At the level of the total group, Cronbach alpha values for each domain ranged from 0.63 (social) to 0.77 (DX) demonstrating good internal consistency overall. Corrected item-total correlations reached 0.4 or higher on all items in the social domain, and 0.3 or higher on all items in the psychological domain. In the remaining three domains, item-total correlations reached at least 0.3 on all but one item, and fell below 0.25 on two items only, indicating possible problems on item 16 (sleep, physical domain) and item 34 (advocacy, DX).

Research Subgroups (hospital, community and general public)

At the level of the research subgroups, the highest alpha values were obtained for the general public group: these ranged from 0.73 (social) to 0.87 (DX). The hospital group alpha values were lower, ranging from 0.58 (social and environment) to 0.71 (DX), and at a similar level to the community group, which ranged from 0.53 (social) to 0.77 (DX).

As noted above, the lowest alpha values obtained were for the social domain. However, Cronbach alpha values for the social domain should be interpreted with caution as the domain comprises only three facets (personal relationships, social support and special relationship/sexual activity) and thus alpha is based on only three item scores. Four item scores would generally be regarded as the minimum required for assessing the internal consistency of a scale (Kline, 1983). However, the methodology used for the present study follows the procedure employed in evaluating the psychometric properties of the base instrument (WHOQOL-BREF) which also has only three items in the social domain (WHOQOL Group, 1998a).

Table 9.7: Reliability Summary for Original Domains and Hypothesised Domain DX

Analysis Level		*N*	Cronbach Alpha					Item-Total Correlations					Possible Problem Items				
	Domain		Ph	Psy	Soc	Env	DX	Ph	Psy	Soc	Env	DX	Ph	Psy	Soc	Env	DX
	No. of Items		*7*	*6*	*3*	*8*	*10*	No. of Items (facets) $r > 0.30$					Items $r < 0.25$				
Total Group		625	0.713	0.692	0.634	0.666	0.774	6	6	3	7	9	16				34
Research Group	Hospital	213	0.660	0.604	0.580	0.579	0.708	5	4	3	3	9	4, 16	7		12	34
	Community	204	0.610	0.614	0.529	0.584	0.769	4	3	3	6	8	16	6		9, 13	34
	Public	208	0.846	0.746	0.728	0.772	0.868	7	6	3	8	10					
WHOQOL Group	ID-Clients/Public	520	0.681	0.645	0.623	0.661	0.758	5	6	3	7	9	16			13	34
(Instrument Version)	ID-Public	103	0.824	0.749	0.718	0.827	0.848	7	5	3	8	10					
	BREF-Public	105	0.881	0.789	0.750	0.699	0.884	7	6	3	7	10				25	
Response Mode	Direct	74	0.611	0.527	0.638	0.650	0.784	4	3	3	4	8	4	6, 26		9	34
	Proxy	343	0.644	0.545	0.547	0.587	0.739	5	4	3	5	9	4, 16	6, 7		12, 13	34
Response Mode and	Hospital-Direct	28	0.649	0.501	0.781	0.508	0.656	4	2	3	3	6	4, 16	7, 26		9, 12, 14, 24	27, 34
Research Group	Community-Direct	46	0.597	0.547	0.317	0.724	0.699	5	4	1	6	7	4, 18	6, 26	20, 21	9	31, 33, 34
	Hospital-Proxy	185	0.658	0.520	0.471	0.590	0.702	5	4	2	5	9	4, 16	6, 7		12	34
	Community-Proxy	158	0.619	0.576	0.556	0.535	0.775	5	4	3	4	8	15, 16	6, 7		9, 12, 13	31, 34

Ph: Physical Psy: Psychological Soc: Social Env: Environment DX: Hypothesised 5th Domain All facets $r > 0.30$ All facets $r > 0.40$

For the public group, corrected item-total correlations reached 0.4 or higher on all items in the physical, social and DX domains, and 0.3 or higher on all items in the psychological and environment domains. Therefore, as no item-total correlations fell below 0.25 in any domain, no items were flagged as problematic for this group.

For the hospital and community groups, corrected item-total correlations reached 0.3 or higher on all items only in the social domain. In the physical domain, possible problem items were flagged by item-total correlations below 0.25 on item 4 (medication) for the hospital group, and item 16 (sleep) for both hospital and community groups. In the psychological domain, possible problems were noted on item 7 (thinking) for the hospital group and on item 6 (spirituality) for the community group. In the environment domain, possible problems were flagged on item 12 (finance) for the hospital group, and items 9 (physical environment) and 13 (information) for the community group. In the hypothesised new domain, DX, item 34 (advocacy) emerged as a possible problem item for both client groups.

The superior outcome for the public group in terms of alpha values and item-total correlations was not unexpected, given that one half of the public group completed the WHOQOL-BREF with the original item wordings, and the reliability of this instrument has been reported with the published psychometric data demonstrating satisfactory levels of internal consistency (WHOQOL Group, 1998a).

WHOQOL Version (combined groups and public group)

The research design allowed the performance of the re-worded WHOQOL-ID to be compared with the established WHOQOL-BREF, with the additional 10 items (hypothesised domain X) included with identical wordings at the end of each version. The WHOQOL-ID as completed both by the two client groups and half of the public performed adequately in terms of internal consistency, showing alpha values ranging from 0.62 (social) to 0.76 (DX). However, consistent with the findings for the research subgroups, a superior range of alpha values was obtained on both versions of the WHOQOL for the general public group only: ID alpha range 0.72 (social) to 0.85 (DX); and BREF alpha range 0.70 (environment) to 0.88 (physical and DX).

The similarity of alpha values for the two versions of the instrument with the general public group (all 0.7 or above) suggested that the adaptation required to customise the WHOQOL-BREF into the WHOQOL-ID for adults with intellectual disabilities (simplified item wording, modified and augmented response format) did not compromise basic instrument reliability in terms of use with people of broadly average intelligence.

However, the more modest alpha values obtained with both the hospital and community client groups suggested the presence of other factors impacting on reliability.

For the WHOQOL-BREF (half public group) corrected item-total correlations reached 0.4 or higher on all items in the physical, psychological, social and DX domains, and 0.3 or higher on all but one item in the environment domain. The one possible problem item highlighted was item 25 (transport). This was a surprising finding on the BREF, for which alpha values of 0.8 on the environment domain had been achieved in original developmental study (WHOQOL Group, 1998a).

For the WHOQOL-ID (half public group) corrected item-total correlations reached 0.4 or higher on all items in the physical and social domains and 0.3 or higher on all items in the environment and DX domains, and on all but one item in the psychological domain. However, as no item-total correlations fell below 0.25 no possible problem items were flagged in this domain for this group.

The analysis of the WHOQOL-ID for the clients and public combined revealed relatively poorer corrected item-total correlations of 0.4 or higher on the social domain only and 0.3 or higher on the psychological domain. Possible problem items emerged in the physical domain on item 16 (sleep), in the environment domain on item 13 (information) and in DX on item 34 (advocacy), all of which had been noted at the research subgroup level of analysis for one or more of the two client groups.

Response Mode (direct and proxy)

The alpha values obtained for the combined client groups in direct and proxy response modes showed a relatively consistent pattern across the domains ranging from 0.53 (psychological) to 0.78 (DX) for direct mode and 0.54 (psychological) to 0.74 (DX) for proxy mode.

In both response modes, the lowest alpha values were obtained for the psychological domain, followed by the social domain (the caveat for which was noted above). Alpha values for the remaining domains were at 0.6 or higher, suggesting adequate internal consistency for a scale at this stage of development and for the numbers involved in this study trial.

For the direct mode, corrected item-total correlations reached 0.4 or higher on all items in the social domain, but fell below the 0.3 threshold on a total of 12 items: three items in the physical domain, three items in the psychological domain, four items in the environment domain and two items in DX. Only five of these item-total correlations fell below the 0.25 threshold such as to be identified as possible problem items: in the physical domain, item 4 (medication); in the psychological

domain items 6 (spirituality) and 26 (negative feelings); in the environment domain item 9 (physical environment); and in DX, item 34 (advocacy).

For the proxy mode, the pattern of corrected item-total correlations was similar, reaching 0.3 or higher on all items in the social domain, but falling below this on eight items in the remaining domains: two items in each of the physical and psychological domains, three items in the environment domain and one item in DX. However, in this mode, the majority of these item-total correlations fell below the threshold of 0.25 also, indicating possible problems: in the physical domain, items 4 (medication) and 16 (sleep); in the psychological domain items 6 (spirituality) and 7 (thinking); in the environment domain items 12 (finance) and 13 (information); and in DX, item 34 (advocacy).

Response Mode and Research Subgroup

The alpha values obtained for the separate client groups in direct and proxy response modes showed a less consistent pattern across the domains for the different subgroups.

For the hospital-direct group, alpha values were 0.6 or higher for three domains (physical, social and DX) suggesting adequate internal consistency. However, low alpha values were obtained for the psychological (0.50) and environment (0.51) domains. For the community-direct group, alpha values were 0.6 or higher for three domains also (physical, environment and DX). However, lower alpha values were found for the psychological (0.55) and social (0.32) domains. These results must be interpreted with caution: firstly, the numbers of participants in each of the direct response groups was small (hospital-direct N=28, community-direct N=46); and secondly, both the highest and lowest alpha value in these data subsets was obtained for the three-item social domain.

For the hospital-proxy group, alpha values were adequate on three domains: 0.59 (environment), 0.66 (physical) and 0.70 (DX); low on one domain: 0.52 (psychological): and very low on one further domain: 0.47 (social). For the community-proxy group, alpha values were adequate on four domains (rounded figures): 0.56 (social), 0.58 (psychological), 0.62 (physical) and 0.77 (DX), but low on one domain: 0.54 (environment). Once again, the lowest alpha value in these data subsets was obtained for the social domain.

For the hospital-direct mode, corrected item-total correlations reached 0.4 or higher on all items in the social domain, but fell below the 0.3 threshold on a total of 16 items: three items in the physical domain, four items in the psychological domain, five items in the environment domain and four items in DX. Furthermore, 10 of these item-total correlations fell below the 0.25 threshold such as to be identified as possible problem items: in the physical domain, items 4 (medication) and 16 (sleep); in the psychological domain, items 7 (thinking) and 26 (negative feelings); in the environment domain, items 9

(physical environment), 12 (finance), 14 (leisure activities) and 24 (health/social care); and in DX, items 27 (stigmatisation) and 34 (advocacy).

For the community-direct mode, corrected item-total correlations did not reach either 0.4 or 0.3 on all items in any domain, and fell below the 0.3 threshold on a 11 items: two items in the physical domain, two items in the psychological domain, two items in the social domain; two items in the environment domain and three items in DX. Furthermore, 10 of these item-total correlations fell below the 0.25 threshold such as to be identified as possible problem items: in the physical domain, items 4 (medication) and 18 (work); in the psychological domain, items 6 (spirituality) and 26 (negative feelings); in the social domain, items 20 (personal relationships) and 21 (special relationship); in the environment domain, item 9 (physical environment); and in DX, items 31 (enabling), 33 (autonomy) and 34 (advocacy).

For the hospital-proxy mode, corrected item-total correlations did not reach 0.4 or 0.3 on all items in any domain, and fell below the 0.3 threshold on 9 items: two items in the physical domain, two items in the psychological domain, one item in the social domain, three items in the environment domain and one item in DX. Six of these item-total correlations fell below the 0.25 threshold such as to be identified as possible problem items: in the physical domain, items 4 (medication) and 16 (sleep); in the psychological domain, items 6 (spirituality) and 7 (thinking); in the environment domain, item 12 (finance); and in DX, item 34 (advocacy).

For the community-proxy mode, corrected item-total correlations reached 0.3 on all items in the social domain, but fell below the 0.3 threshold on 10 items: two items in the physical domain, two items in the psychological domain, four items in the environment domain and two item in DX. Furthermore, 9 item-total correlations fell below the 0.25 threshold such as to be identified as possible problem items: in the physical domain, items 15 (mobility) and 16 (sleep); in the psychological domain, items 6 (spirituality) and 7 (thinking); in the environment domain, item 9 (physical environment), 12 (finance) and 13 (information); and in DX, items 31(enabling) and 34 (advocacy).

Summary of Stage One of Reliability Analysis

A summary of stage one of the reliability analyses is presented in Tables 9.8 and 9.9. Overall the adapted WHOQOL-ID performed adequately in terms of reliability for all research groups and in both response modes; and good reliability was demonstrated for the hypothesised domain DX at all levels of analysis.

As shown in Table 9.8, for all the main participant groups, alpha values were 0.6 or higher on all domains with the exception of the social domain for the community group.

Table 9. 8: Summary of Alpha Values by Domain for Main Participant Groups

Group	*N*	Cronbach Alpha				
		Ph	Psy	Soc*	Env	DX
Hospital	213	0.7	0.6	0.6	0.6	0.7
Community	204	0.6	0.6	0.5	0.6	0.8
Public-ID	103	0.8	0.7	0.7	0.8	0.8
Public-BREF	105	0.9	0.8	0.8	0.7	0.9
Total Group	625	0.7	0.7	0.6	0.7	0.8

Ph: Physical Psy: Psychological Soc: Social Env: Environment DX: Hypothesised 5th Domain
* Only 3 items, therefore Cronbach alpha may not be reliable

For the general public, alpha values for the ID version of the instrument were of the same order as achieved for the BREF (ID α range 0.7-0.8; BREF α range 0.7-0.9), which in turn were consistent with the alpha values (BREF α range 0.7-0.8) obtained in the original developmental study (WHOQOL Group, 1998a).

Alpha values for the hypothesised additional domain DX ranged from 0.7 for the hospital group to 0.8 and 0.9 for the two public groups (both of which responded to exactly the same wording and format for DX items), suggesting that this domain also demonstrated good internal consistency for all groups.

As shown in Table 9.9, for the ID client groups (hospital and community combined) alpha values for the separate response modes ranged from 0.5 (psychological) to 0.8 (DX).

Table 9. 9: Summary of Alpha Values by Domain for Response Modes

ID Client Subgroup	*N*	Cronbach Alpha				
		Ph	Psy	Soc*	Env	DX
Direct Response	74	0.6	0.5	0.6	0.6	0.8
Proxy Response	343	0.6	0.5	0.5	0.6	0.7

Ph: Physical Psy: Psychological Soc: Social Env: Environment DX: Hypothesised 5th Domain
* Only 3 items, therefore Cronbach alpha may not be reliable

Slightly lower alpha values were obtained for the psychological domain (0.5) in both direct and proxy mode, compared with that achieved for hospital and community groups irrespective of response mode (0.6). However, as previously shown in Table 9.7, the proxy group only just fell below the criterion for rounding upwards ($\alpha = 0.545$) rather than downwards; and for the direct response

mode, the very much smaller group size may have contributed to the lower alpha value ($\alpha = 0.527$).

In direct and proxy response mode, once again the highest alpha values were obtained for DX; and these were consistent with the alpha values obtained for the separate hospital and community groups for this hypothesised domain.

Possible Problem Items

Across the six levels of analysis, possible problems (as defined by corrected item-total correlations below 0.25) were flagged on 19 items in the five domains: physical (four items), psychological (three items), social (two items), environment (six items) and DX (four items).

WHOQOL Base Domains

Of the 19 items flagged as possible problem items, 15 related to items from the original WHOQOL scale. These items are presented by domain in Table A9.14, and by group/subgroup and level of analysis in Table A9.15, both in Appendix 9.

In the WHOQOL-100 study (WHOQOL Group, 1998b) these 15 items demonstrated *item-facet* correlations ranging from 0.36 (physical environment) to 0.84 (work) in the context of an overall structure of 24 four-item facets and six domains. Only three of these 15 items subsequently selected for the WHOQOL-BREF had the highest item-facet correlation of their subset (work, 0.84; personal relationships, 0.57; and sexual activity, 0.77); and two items had item-facet correlations below 0.5 (physical environment, 0.36; and thinking, 0.48). The selection of these items for the shortened version of the instrument was based on a range of reliability and validity criteria, not solely on the level of these correlations. Ultimately, the BREF has been shown to be a reliable and valid instrument.

However, the relatively poorer *item-domain* correlations obtained on these items in the present study may have related to some of the issues discussed in terms of item re-wording (possible inadequacy in relation to the level of cognitive ability of participants in the hospital patient and community client groups) or maintenance of semantic equivalence (possible simplification achieved at the expense of precision of meaning) in the adapted WHOQOL-ID version of the instrument

It is noteworthy that no corrected item-total correlation fell below 0.25 on the WHOQOL-ID completed by the public group only; and only one item (25, transport) fell below this level on the WHOQOL-BREF completed by the public. This suggested that the adapted scale had adequate internal consistency with members of the general public (with broadly average levels of intellectual ability).

However, the evidence suggested that further work may be required on the wording and semantic equivalence of these 15 items for use with an intellectually disabled group.

Additional Domain DX

The remaining four possible problem items related to four of the 10 new items introduced within the hypothesised additional domain DX. These items are summarised by group/subgroup and level of analysis in Table 9.10.

Table 9.10: Possible Problem Items – Domain DX

Item	Facet	Group/Subgroup	Analysis Level	*N*	Corrected Item-Total Correlation
27	Stigmatisation	Hospital-Direct	6	28	0.01
31	Enabling	Community-Direct	6	46	0.23
		Community-Proxy	6	158	0.24
33	Autonomy	Community-Direct	6	46	0.13
34	Advocacy	Total	1	625	0.15
		Hospital	2	213	-0.18
		Community	2	204	0.15
		WHOQOL-ID (client/public)	3	520	0.11
		Direct Response	5	74	0.13
		Proxy Response	5	343	-0.00
		Hospital-Direct	6	28	0.06
		Community-Direct	6	46	-0.16
		Hospital-Proxy	6	185	-0.18
		Community-Proxy	6	158	0.16

Items 27, 31, and 33 showed poor corrected item-total correlations only within the response mode analysis; and items 27 and 33 reflected poor corrected item-total correlations within the context of the smallest of the analysis subgroups i.e. direct response. Of greater concern was item 34, which was problematic within the larger subgroups, across almost every level of analysis. Of these four items only item 27 was flagged with possible frequency problems, having over 80% of responses at the extreme scale points; and none of the four items had high levels of missing values at any level of analysis.

Item 34 showed poor corrected item-total correlations within the hospital and community research groups, but not for the general public, despite these subjects receiving the same item (with the same wording) on both versions of the scale. It was possible that the directional strength of the 'advocacy' item varied between subject groups (ID clients and general public), tapping both positive attributes (e.g. accepting and embracing help and support when needed) and conveying negative signals (e.g. of diminished capacity). There may have been contextual issues for individual respondents also, even those without intellectual disabilities,

as the item was highlighted as problematic for both clients responding directly, and proxy respondents (staff), although not for the public.

As shown in Table 9.10, the corrected item-total correlations were so low, at so many levels of analysis that it appeared item 34 made no contribution at all to its domain. For this reason, a second stage of the reliability analysis was carried out for domain DX to investigate the effect of removing the problem items (principally item 34) from the scale.

9.3.2 Domain DX and Item Variations

The reliability analysis was repeated for DX, in order to determine the most effective number and combination of items for this domain, based on the impact on reliability and contribution to the overall subscale. The summary of this second stage of reliability analysis is presented in Table 9.11.

(In order to aid clarity, the Cronbach alpha values for domain DX with all ten items included are shown in black (replicated exactly from Table 9.7). In successive columns, the values for DX with item 34 removed appear in pink; the values for DX with both items 34 and 31 removed are green; the values for DX with items 34, 31, 33 and 27 removed are turquoise; and the values for DX with items 34, 31, 33, 27 and 32 removed are violet).

DX - Item 34

As shown in Table 9.11, the effect of removing item 34 from DX was that Cronbach alpha values improved for all groups and subgroups, at all levels of analysis.

In addition, corrected item-total correlations reached 0.4 or higher on all items (facets) in four out of the 13 groups/subgroups, and 0.3 or higher on all items in a further four groups/subgroups (compared with two groups and one group respectively for the full 10-item DX). A further five groups/subgroups failed to reach the 0.3 threshold on all items.

For the community group, when item 34 was removed, item 31 (enabling) emerged as a possible problem item (defined by item-total correlation $r < 0.25$). Although this was not flagged as a possible problem item for this group in the analysis of the full DX, it was noted in relation to the two community subgroups by response mode. However, in the absence of item 34, item 31 no longer fell below the 0.25 threshold for the community-direct group, although it did so for the community-proxy group.

This suggested that item 31 had lower reliability in connection with proxy respondents in community settings ($r = 0.19$), although this was not the case for proxies in the hospital ($r = 0.44$).

Table 9.11: Reliability Summary for Hypothesised Domain DX and Item Variations

Analysis Level		*N*	Cronbach Alpha					Item-Total Correlations					Possible problem Items				
Base Domain (excluded items)			DX	- 34	- 31, 34	- 27, 31, 33, 34	- 27, 31, 32, 33, 34	DX	- 34	- 31, 34	- 27, 31, 33, 34	- 27, 31, 32, 33, 34	DX	- 34	- 31, 34	- 27, 31, 33, 34	- 27, 31, 32, 33, 34
	No. of Items		*10*	*9*	*8*	*6*	*5*	No. of Items (facets) $r > 0.30$					Items $r < 0.25$				
Total Group		625	0.774	0.811	0.809	0.788	0.791	9	9	8	6	5	34				
Research Group	Hospital	213	0.708	0.778	0.769	0.746	0.775	9	9	8	5	5	34			32	
	Community	204	0.769	0.796	0.815	0.805	0.789	8	8	7	6	5	34	31			
	Public	208	0.868	0.873	0.860	0.838	0.820	10	9	8	6	5					
WHOQOL Group	ID-Clients/Public	520	0.758	0.798	0.798	0.779	0.781	9	9	8	6	5	34				
(Instrument Version)	ID-Public	103	0.848	0.857	0.833	0.806	0.772	10	9	8	6	5					
	BREF-Public	105	0.884	0.884	0.880	0.862	0.856	10	9	8	6	5					
Response Mode	Direct	74	0.784	0.804	0.794	0.798	0.774	8	8	8	6	5	34				
	Proxy	343	0.739	0.787	0.794	0.771	0.784	9	9	8	6	5	34				
Response Mode and	Hospital-Direct	28	0.656	0.676	0.671	0.707	0.696	6	6	6	6	5	27, 34	27, 31	27		
Research Group	Community-Direct	46	0.699	0.769	0.769	0.781	0.755	7	7	7	6	4	31, 33, 34	33	33		
	Hospital-Proxy	185	0.702	0.778	0.763	0.734	0.776	9	9	8	5	5	34			32	
	Community-Proxy	158	0.775	0.800	0.826	0.809	0.797	8	8	8	6	5	31, 34	31			

No further possible problem items emerge

DX: Hypothesised 5th Domain All facets $r > 0.30$ All facets $r > 0.40$

Given the item wording *(How often do you get to say what you want to do in your day-to-day life?)* this may have reflected the ideological bias of proxy respondents in community settings, and suggested patterns of responding influenced by social desirability, particularly as no similar problem emerged for the hospital group.

In contrast, item 31 was flagged as a possible problem item for the hospital-direct group ($r = 0.24$), as was item 27 ($r = 0.01$). Similarly, item 33 remained as a possible problem item for the community-direct group ($r = 0.10$). However, caution was required in interpreting the latter three results in view of the small size of the hospital and community direct response groups (N=28 and N=46 respectively).

DX – Items 31 and 34

As shown in Table 9.11, the effect of removing both items 31and 34 from DX was that Cronbach alpha values changed very little from the set of values with only item 34 removed. Alphas showed a slight improvement (at the level of two decimal places) for two groups/subgroups only (community and community-proxy), remained at the same level for five groups/subgroups, and reduced very slightly (also at the level of two decimal places) for six groups/subgroups.

Corrected item-total correlations reached 0.4 or higher on all items (facets) in three out of the 13 groups/subgroups, and 0.3 or higher on all items in a further seven groups/subgroups (compared with four groups and four groups respectively for the full 9-item DX with only item 34 removed). Only three groups/subgroups failed to reach the 0.3 threshold on all items.

For the two smallest subgroups, two items remained as possible problem items. However, this finding required the same cautious interpretation as noted previously. For the hospital-direct group, when both items 31 and 34 were removed, item 27 (stigmatisation) emerged as a possible problem item (defined by item-total correlation $r < 0.25$). This was flagged as a possible problem item for this group in the analysis of both the full DX, and DX-34 also.

For the community-direct group, when both items 31 and 34 were removed, item 33 (autonomy) emerged as a possible problem item. This too was flagged as a possible problem item for this group in the analysis of both the full DX, and DX-34 also.

DX – Items 27, 31, 33 and 34

As shown in Table 9.11, the effect of removing items 27, 31, 33 and 34 from DX was that Cronbach alpha values showed a very slight decline from the set of values with only item 34 removed (used as the comparator with the highest set of values overall).

Alphas showed slight improvement (at the level of two decimal places) for four groups/subgroups (community group, hospital-direct, community-direct and community-proxy), remained at the same level for one group/subgroup, but reduced very slightly (also at the level of two decimal places) for eight groups/subgroups, including some of the major groupings (total group, hospital group, general public group, proxy response).

However, corrected item-total correlations reached 0.4 or higher on all items (facets) in six out of 13 groups/subgroups, and 0.3 or higher on all items in a further five groups/subgroups (compared with four groups and four groups respectively for the full 9-item DX with only item 34 removed). Only two groups/subgroups failed to reach the 0.3 threshold on all items.

For both the hospital group and the hospital-proxy subgroup, when items 27, 31, 33 and 34 were removed, item 32 (empowerment) emerged as a possible problem item (defined by item-total correlation $r < 0.25$). This was not flagged as a possible problem item for these groups/subgroups in the analysis of either the full DX, or any of the variations on DX examined thus far.

This suggests that item 32 had lower reliability for hospital patients ($r = 0.24$), than for either community clients ($r = 0.50$) or the general public ($r = 0.57$). To some extent it appears that the differential reliability may be accounted for by the effect of proxy response mode for the hospital group. The item-total correlation of item 32 for the hospital-proxy subgroup was lower ($r = 0.20$) than that for the hospital-direct subgroup ($r = 0.34$), and for community-proxy ($r = 0.48$) and community-direct ($r = 0.52$).

Given the item wording (*How often do other people listen to what you want?*) this may have reflected the impact of the institutional setting and its regime. Hospital proxy staff may have been influenced by policies and practices geared more to the requirements of large-group living than individual preferences and choices. Furthermore, the WHOQOL assessments were undertaken in the hospital during a programme of resettlement heralding change for both residents and staff. At this time, social work and social care teams located outside the hospital may have driven much of the contemporaneous planning and decision-making. The hospital staff may have felt disempowered and this, in turn, may have influenced their judgements on this item on behalf of their patients.

DX – items 27, 31, 32, 33 and 34

As shown in Table 9.11, the effect of removing items 27, 31, 32, 33 and 34 from DX was that Cronbach alpha values showed a slight decline from the set of values with only item 34 removed (used as the comparator with the highest set of values overall).

Alphas showed slight improvement (at the level of two decimal places) for one subgroup (hospital-direct), remained at the same level for two groups/subgroups,

but reduced very slightly (also at the level of two decimal places) for 10 groups/subgroups, including most of the major groupings (total group, hospital group, community group, general public group, direct response, proxy response).

However, corrected item-total correlations improved considerably reaching 0.4 or higher on all items (facets) in 13 out of 13 groups/subgroups, and only one subgroup (community-direct) failed to reach the 0.3 threshold on all items. In addition, no further problem items emerged as all corrected item-total correlations were higher than 0.25.

Summary of Stage Two of Reliability Analysis

The picture that emerged from the repeated range of analyses is somewhat ambiguous. On the one hand, domain DX based on nine items (with item 34 only removed) achieved the highest set of alpha values overall, although there were only minor variations in values across the different item conditions. On the other hand the highest set of corrected item-total correlations was obtained for domain DX based on only five items (with items 27, 31, 32, 33, and 34 removed). Furthermore, in the five-item configuration of DX, corrected item-total corrections were 0.25 or higher on all items, so the < 0.25 criterion for possible problems was exceeded.

This indicated that a DX scale based on either nine or five items would have superior reliability compared with the base 10-item DX; but the impact on corrected item-total correlations of the five-item scale, at the expense of almost negligible decline in alpha values, suggested that this might be a more robust configuration.

However, inspection of the facet content of the items that would be included and excluded to produce this modified scale revealed thematically different item clusters, suggesting the possibility of two subscales rather than one. Consistent with the findings thus far, the 10 DX items could be divided into two thematic groups reflecting the potential for positive or negative attitudes, emotions or behavioural responses to people with intellectual disability as shown in Table 9.12.

Table 9.12: Thematic Item Groups - Hypothesised Domain DX

Response	Positive-supportive-inclusive		Negative-detracting-exclusive	
	Item	Facet	Item	Facet
Presence	31	Enabling	27	Stigmatisation
	32	Empowerment	28	Victimisation
	33	Autonomy	29	Ridicule
	34	Advocacy	30	Discrimination
Absence			35	Respect
			36	Acceptance

These thematic groups of items could be seen as comprising two separate sub domains of the original domain DX. Therefore a third stage of the reliability analysis was carried out for domain DX to investigate the effects of reconfiguring the ten-item scale into two sub domains DY and DZ.

9.3.3 Domain DX and Sub Domain Variations

The reliability analysis was repeated for DX, in order to determine the impact on reliability of a structure based on two separate domains (i.e. two sub domains of DX) and to examine the most effective item combination for these DY and DZ domains. The summary of this third stage of reliability analysis is presented in Table 9.13.

(In order to aid clarity, the Cronbach alpha values for the original domain DX with all ten items included are shown in black (replicated exactly from Tables 9.7 and 9.11). In successive columns, the values for DY with six items appear in pink; the values for DY with five items are green; the values for DZ with four items are turquoise; and the values for DZ with three items are violet).

DY (1) and DZ (1)

The first two-domain item configuration examined was based on the thematic clusters identified in Table 9.12. This had the benefit of maximising the use of data from all ten DX items in two groups: DY comprising items 27, 28, 29, 30, 35 and 36; and DZ comprising items 31, 32, 33 and 34.

The reliability comparator for the DY (1) and DZ (1) structures was that established for DX and for DX-34 in stage two, according to the superiority of each of these on different components of the reliability analysis.

DY (six items)

The effect of a six-item DY can be seen from Tables 9.11 and 9.13: Cronbach alpha values improved for eight out of the 13 groups and subgroups, compared with the original 10-item DX; and remained at similar levels overall compared with those achieved for the nine-item DX (DX-34). Alpha values were 0.8 or higher (rounded figures) for all major groups and all but the smallest subgroup (hospital-direct, N=28). This suggested that DY was a robust domain on this measure of reliability.

In addition, corrected item-total correlations reached 0.4 or higher on all items (facets) in 10 out of the 13 groups/subgroups, and 0.3 or higher on all items in one further group/subgroup (compared with four and four groups/subgroups respectively for DX-34).

Table 9.13: Reliability Summary for Domain DX and Sub Domain Variations DY and DZ

Analysis Level		*N*	Cronbach Alpha					Item-Total Correlations					Possible Problem Items				
Domain (excluded items)			DX	DY	DY (-27)	DZ	DZ (-34)	DX	DY (1)	DY (2)	DZ (1)	DZ (2)	DX	DY (1)	DY (2)	DZ (1)	DZ (2)
Included Items			All 10 (27-36)	27, 28, 29, 30, 35, 36	28, 29, 30, 35, 36	31, 32, 33, 34	31, 32, 33										
No. of Items			*10*	*6*	*5*	*4*	*3*	No. Items *r* (facets) > 0.30					Items *r* < 0.25				
Total Group		625	0.774	0.814	0.791	0.592	0.732	9	6	5	3	3	34			34	
Research Group	Hospital	213	0.708	0.793	0.775	0.575	0.780	9	6	5	3	3	34			34	
	Community	204	0.769	0.818	0.789	0.607	0.676	8	6	5	3	3	34			34	
	Public	208	0.868	0.843	0.820	0.706	0.766	10	6	5	4	3					
WHOQOL Group	ID-Clients/Public	520	0.758	0.803	0.781	0.606	0.738	9	6	5	3	3	34		No further possible problem items emerge	34	
(Instrument Version)	ID-Public	103	0.848	0.784	0.772	0.722	0.776	10	6	5	4	3					
	Bref-Public	105	0.884	0.881	0.856	0.693	0.754	10	6	5	3	3					
Response Mode	Direct	74	0.784	0.773	0.774	0.563	0.688	8	6	5	3	3	34			34	
	Proxy	343	0.739	0.816	0.784	0.615	0.762	9	6	5	3	3	34			34	
Response Mode and	Hospital-Direct	28	0.656	0.643	0.696	0.381	0.490	6	5	5	1	2	27, 34	27		31, 34	31
Research Group	Community-Direct	46	0.699	0.785	0.755	0.210	0.656	7	5	4	1	2	31, 33, 34			34	33
	Hospital-Proxy	185	0.702	0.806	0.776	0.617	0.821	9	6	5	3	3	34			34	
	Community-Proxy	158	0.775	0.829	0.797	0.609	0.666	8	6	5	3	3	31, 34				

DX: Hypothesised 5th Domain DY and DZ: Hypothesised Sub domains of DX All facets $r > 0.30$ All facets $r > 0.40$

Only the two smallest subgroups failed to reach the 0.3 threshold on all items (hospital-direct and community-direct).

Only one possible problem item (defined by item-total correlation $r < 0.25$) emerged from the six-item DY configuration: this was item 27 (stigmatisation) for the hospital-direct subgroup. This item was flagged as a possible problem item for this subgroup in the analysis of both the full DX and DX-34 also.

DZ (four items)

In contrast, the effect of a four-item DZ was that Cronbach alpha values declined for all 13 groups and subgroups, compared with both the original ten-item DX and the nine-item DX-34 (and were lower than those achieved for the five-item DX also). As shown in Table 9.12, alpha values for DZ ranged from 0.21 (community-direct) to 0.72 (WHOQOL-ID public group), but fell below 0.7 for ten out of the thirteen groups/subgroups and below 0.6 for the two smallest subgroups. This suggested that DZ was not a robust domain on this measure of reliability.

In addition, corrected item-total correlations did not reach 0.4 or higher on all items (facets) in any of the 13 groups/subgroups, and reached 0.3 or higher on all items in two groups/subgroups only.

Item 34 (advocacy) emerged as a possible problem item (defined by item-total correlation $r < 0.25$) in a total of nine groups/subgroups, including the major ID client groupings (hospital group, community group, direct response, proxy response) replicating the finding from the analysis of the original DX, and despite the apparent thematic consistency of advocacy with the other DZ items. These two findings taken together suggested that item 34 (as currently worded) should be dropped from the WHOQOL-ID.

The only other possible problem item that emerged from the four-item DZ was item 31 (enabling) for the hospital-direct subgroup. This item was flagged as a possible problem item for this subgroup in the analysis of both the full DX and DX-34 also.

DY (2) and DZ (2)

The second two-domain item configuration examined was determined by the outcome of the reliability analysis of DY (1) and DZ (1). Since item 27 had emerged as the only possible problem item for DY (1), it was dropped from DY (2); and since item 34 had emerged as the major problem item in DZ (1), it was dropped from DZ (2). Therefore, for this phase of analysis DY (2) became a five-item domain, comprising items 28, 29, 30, 35 and 36, and DZ (2) reduced to a three-item domain comprising items 31, 32 and 33.

The reliability comparators for the DY (2) and DZ (2) structures were the reliability levels established for DY (1) and DZ (1).

DY (five items)

The effect of a five-item DY (2) can be seen from Table 9.12: Cronbach alpha values declined slightly in 10 out of 13 groups/subgroups compared with DY (1). However, for DY (2) as for DY (1), alpha values were 0.8 or higher (rounded figures) for all major groups and all but the smallest subgroup (hospital-direct, N=28).

Corrected item-total correlations reached 0.4 or higher on all items (facets) in twelve out of the thirteen groups/subgroups, but failed to reach 0.3 or higher on all items in the remaining subgroup. In addition, no item-total correlations fell below 0.25 and hence no further possible problem items were noted.

DZ (three items)

As shown in Table 9.12, the effect of a three-item DZ (2) was that Cronbach alpha values improved for all 13 groups and subgroups, compared with DZ (1). Overall, DZ (2) performed better than DZ (1) as alpha values for DZ (2) ranged from 0.49 (hospital-direct) to 0.82 (hospital-proxy) and fell below 0.7 (and also below 0.6) only for the smallest subgroup, hospital-direct.

In addition, corrected item-total correlations reached 0.4 or higher on all items (facets) in 11 of the 13 groups/subgroups, and failed to reach 0.3 or higher on all items in the two smallest subgroups only. Two possible problem items (as defined by $r < 0.25$) emerged from these two subgroups: item 31 (enabling) for hospital-direct (flagged for this subgroup for DZ (1) also) and item 33 (autonomy) for community-direct. However, caution was required in relation to this finding, as these subgroups were very small, and this configuration of DZ comprised only three items in total.

Summary of Stage Three of Reliability Analysis

Overall, the picture that emerged from this stage of analysis tended to confirm that the hypothesised DX might best be regarded as a composite of two separate domains DY and DZ.

It appeared that the DY domain has adequate reliability with either five or six items included, but might be most robust in its six-item DY (1) configuration. The most reliable configuration of the DZ domain was the three-item DZ (2), although the same caution as noted in terms of the WHOQOL-BREF three-item social domain applies to DZ, as four item scores is generally regarded as the minimum required for assessing the internal consistency of a scale.

In this two-domain configuration, the only item to be dropped from the initial scale remained item 34 (advocacy). Effectively, DY (1) and DZ (2) equated to DX-34. Overall, DY (1) had superior reliability to DX-34 and could be seen as a six-item DX. The reliability figures for DZ (2) were slightly poorer. However, the division of the nine-item DX (DX-34) into DY (six items) and DZ (three items) appeared to provides a more satisfactory thematic explanation of the content of the originally hypothesised DX as DY: a social inclusion-exclusion dimension; and DZ: an empowerment dimension.

9.4 Correlations

In addition to the corrected item-total correlations undertaken as part of the scale reliability analyses, further correlations were carried out to determine whether any WHOQOL-ID item loaded higher on another domain than its own predicted domain.

This was relevant to the reworded items within the four original WHOQOL domains (physical, psychological, social and environment), but of particular importance in terms of the 10 items written specifically for the facets in the hypothesised domain DX (or the nine out of 10 items posited for the two smaller domains DY and DZ).

It was possible that one or more of these new ID items might load higher on one of the four base domains (for example the psychological or environment domains) rather than on the predicted domain of DX, or in the alternative structure, DY or DZ. This would suggest that such items might be more appropriately placed in these domains, or might be tapping quality of life facets already included in the scale.

The pattern of significant item-domain correlations (as defined by $r > 0.4$) across domains was inspected also. It was possible that some items might load highly on the predicted domain, but also show a significant loading on one or more additional domains.

Some item-domain cross-correlations would be predictable, given the global nature of the quality of life scale and the definitions of constituent facets (items): for example, item 10 (energy) loading on both its own physical domain and on the psychological domain. However, it was possible that some items might show significant but non-predicted associations with a domain on which the item should not load, flagging possible problems with that item.

As such problem items were excluded from the original WHOQOL-100 and the BREF in the process of scale development, non-predicted loadings would not be expected on items in the four base domains of the adapted WHOQOL-ID. Thus any significant non-predicted correlations identified on base domain items might

relate to specific (identifiable) characteristics of the study participants, or might flag problems associated with item re-wording or semantic equivalence. However, as the new items in domain DX had not been subject to previous psychometric evaluation, significant non-predicted loadings might identify possible problem items that should be considered for exclusion from the final version of the WHOQOL-ID.

The correlation analysis was conducted in two stages:

> *Stage One:* Analysis of the original four WHOQOL-BREF base domains (physical, psychological, social and environment) and the originally hypothesised additional (ID) domain DX.
>
> *Stage Two:* Analysis of the single domain structure of DX compared with the alternative two domain structures of DY and DZ.

9.4.1 WHOQOL Base Domains and DX

The correlations for the four original WHOQOL domains and the additional hypothesised domain (DX) were conducted according to the six levels of analysis and the results are presented in full in Tables A9.16 - A9.21 in Appendix 9.

Total Group

Item-domain correlations

As shown in Table A9.16, at the level of the total group, all items associated with all four base domains (physical, psychological, social and environment) showed the highest correlation with the predicted domain in each case. However, item 16 (sleep) in the physical domain showed a relatively lower item-domain correlation ($r < 0.4$) than the other items. Item 16 also demonstrated a poor corrected item-total correlation when its contribution to the domain was excluded. In domain DX, nine out of ten items showed the highest level of correlation with the predicted domain. However, item 34 (advocacy) showed a higher correlation with the non-predicted psychological domain ($r = 0.45$) than with the predicted DX ($r = 0.39$). Item 34 also demonstrated poor corrected item-total correlation when its contribution to domain DX was excluded.

Cross-correlations

Nine items showed significant cross-correlations (as defined by $r > 0.4$) with other domains, although having the highest correlation with the predicted domain.

In the physical domain, items 10 (energy), 17 (activities of daily living) and 18 (work) cross-correlated with the psychological domain; and items 17 (activities of daily living) and 18 (work) also cross-correlated with the environment domain. In the psychological domain, both items 5 (positive feelings) and 19 (self-esteem) also loaded significantly on the physical, social and environment domains. In the social domain, item 20 (personal relationships) cross-correlated with the psychological and environment domains; and item 22 (social support) cross-correlated with the environment domain. Finally, in the environment domain item 23 (home) showed significant loading on the social domain.

In the four base domains, the relationship between all these items and their predicted and associated domains is explicable (and, to varying extent, predictable) in terms of item content, facet definition or the characteristics of the study participants.

However, in domain DX, item 34 (advocacy) not only showed a significant cross-correlation with the psychological domain, but this was higher than that achieved on DX. This further confirmed the problematic nature of this item as identified in the reliability analysis. In isolation, the pattern of item-domain correlations suggested that item 34 would be placed more appropriately in the psychological domain, but in combination with other aspects of the scale analysis, provided additional support for excluding this item from the WHOQOL-ID.

Research Subgroups (hospital, community and general public)

Item-domain correlations

As shown in Table A9.17, at the level of the research subgroups, all items associated with all four base domains showed the highest correlation with the predicted domain for hospital, community and general public groups. However, three items showed relatively poor item-domain correlations ($r < 0.4$) for the two client groups: item 4 (medication) for the hospital group; item 16 (sleep) for hospital and community groups; and item 9 (physical environment) for the community group. These items also demonstrated poor corrected item-total correlation when their individual contribution to the item-domain correlation was excluded.

In DX, item 34 (advocacy) showed almost negligible correlation ($r = 0.03$) with its predicted domain, having a higher correlation (although at the low level of $r = 0.17$) with the non-predicted physical domain for the hospital group; and showed relatively low item-domain correlation ($r = 0.37$) for the community group. For the public group, all items in DX showed the highest correlation with the predicted domain.

Cross-correlations

For the hospital and community groups, nine items showed significant cross-correlations ($r > 0.4$) with other domains although having the highest level of correlation with the predicted domain.

In the physical domain, item 17 (activities of daily living) cross-correlated with the psychological domain for the hospital group and with DX for the community group; and item 18 (work) cross-correlated with the psychological domain for the hospital group, and with the psychological, environment and DX domains for the community group. In the psychological domain, item 5 (positive feelings) cross-correlated with the physical, social and environment domains for the hospital group, and with the social and environment domains for the community group; item 11 (body image) cross-correlated with the physical domain for the hospital group only; and item 19 (self-esteem) cross-correlated with the physical and social domains for the hospital group, and with the environment domain for the community group. In the environment domain, item 14 (leisure activities) cross correlated with the physical domain for the community group; item 23 (home) cross-correlated with the social domain for the both hospital and community groups; and item 24 (health/social care) cross-correlated with the social domain for the hospital group only.

Once again, in the four base domains, the relationship between all these items and their predicted and associated domains can be explained in terms of item content, facet definition or the characteristics of the groups.

In domain DX, item 32 (empowerment) showed a significant cross-correlation with the environment domain for the community group, although this was not evident for the hospital group. This may reflect the impact of community resettlement on clients and the extent to which the smaller and less restricted setting of community homes (as compared with hospital) contributes to, or supports, greater self-determination.

For the general public group, 23 items showed significant cross-correlations ($r > 0.4$) with other domains although having the highest level of correlation with the predicted domain. Of these, 17 items were linked with the original four WHOQOL domains on which the two halves of the public group responded to the different item wordings contained in the ID and BREF versions of the instrument. For this reason, these findings are discussed in relation to the outcomes from the two public groups separately (see WHOQOL Versions).

In domain DX, the public responded to identical items (exactly as for the ID clients) whichever version of the instrument was completed. As shown in Table A9.17, six items demonstrated significant cross-correlations with other domains for the public: items 28 (victimisation) and 31 (enabling) cross-correlated with the environment domain; item 32 (empowerment) cross-correlated with the psychological, social and environment domains; items 33 (autonomy) and 35

(respect) cross-correlated with the environment domain; and 36 (acceptance) cross-correlated with the psychological, social and environment domains.

These associated domain correlations could be predicted from item content and facet definition; and, as all these cross-correlations were of a lower order than that for the predicted domain DX (range for these six items 0.63 – 0.76), this provided some support for the original hypothesis that these items were placed appropriately in DX rather than in any other domain.

It was noted also that item 34 (advocacy) which showed the lowest item-domain correlation ($r = 0.54$) in DX, did not show any significant cross-correlation with any other domains for the public group.

WHOQOL Version (ID - combined clients and general public)

The pattern of item-domain correlations and cross-correlations for the combined client groups plus one half of the public ($N = 520$), all of whom completed the WHOQOL-ID version of the instrument, showed marked similarity to that of the total group ($N = 625$) overall. There were similarities to the pattern of correlations noted for the separate hospital and community groups also. This outcome may be related to aspects of the ID version of the instrument (e.g. specific item wording) but may be a simple reflection of the disproportionate weighting of numbers of the ID clients in this combined group, and the impact of their characteristics.

Item-domain correlations

As shown in Table A.9.18, all items associated with the four base domains showed the highest level of correlation with the predicted domain for this group. However, item 16 (sleep) in the physical domain showed a relatively lower item-domain correlation, at the same level as for the total group ($r = 0.34$).

In domain DX, nine out of 10 items showed the highest level of correlation with the predicted domain, but item 34 (advocacy) demonstrated a higher correlation with the non-predicted psychological domain (although this was marginal at the level of two decimal places).

Cross-correlations

Seven items showed significant cross-correlations ($r > 0.4$) with other domains, although having the highest correlation with the predicated domain.

In the physical domain, items 17 (activities of daily living) and 18 (work) cross-correlated with the psychological domain; and item 18 (work) also cross-correlated with the environment domain. In the psychological domain, both items 5 (positive feelings) and 19 (self-esteem) also loaded significantly on the

physical, social and environment domains. In the social domain, item 20 (personal relationships) cross-correlated with the psychological and environment domains; and item 22 (social support) cross-correlated with the environment domain. Finally, in the environment domain item 23 (home) showed significant loading on the social domain.

In domain DX, no cross-correlations were found at the specified level of 0.4 or higher. However, item 34 (advocacy) demonstrated correlations at similar levels in three domains: physical ($r = 0.33$), psychological ($r = 0.35$) and the predicated DX ($r = 0.34$).

WHOQOL Version (ID and BREF - general public)

Overall, the findings for the two halves of the public group were similar for both the ID and BREF versions of the instrument, consistent with that achieved by the public group as a whole, and contrasted with the pattern of findings for ID subjects.

Item-domain correlations

As shown in Table A.9.19, all items associated with the four base domains showed the highest level of correlation with the predicted domain on both the ID and BREF versions of the instrument completed by the public group. No item-domain correlations fell below 0.4, and the level of correlation of items with the predicted domain was of a similar order for both instruments (ID range 0.49 – 0.89; BREF range 0.42 – 0.84), irrespective of differences in item wording.

In domain DX, all items showed the highest correlation with the predicted domain on both versions of the instrument. Item 34 (advocacy) achieved the lowest item-domain correlation on each version (ID: 0.51; BREF: 0.58) but did not fall below the threshold of concern ($r < 0.4$) as noted for the hospital and community groups.

Cross-correlations

For the public-ID and public-BREF groups, a large proportion of items (27 and 26 respectively) showed significant cross-correlations ($r > 0.4$) with other domains although having the highest level of correlation with the predicted domain. Of these, 20 and 19 items respectively were in the four base domains on which the two halves of the public group responded to the different item wordings contained in the ID and BREF versions of the instrument. On the assumption of homogeneity of the two halves of the public group, the BREF results provided the standard against which to evaluate these cross-correlations as its reliability and validity has been demonstrated (WHOQOL Group, 1998a).

Overall, the pattern of item correlation with associated (non-predicted) domains was similar on the two versions of the instrument. The only differences of note related to three items: item 15 in the physical domain, and items 12 and 25 in the environment domain.

Item 15 (mobility) correlated highly with the predicted domain ($r = 0.79$) on the BREF and did not show significant cross-correlations. On the WHOQOL-ID, item 15 correlated highly with the predicted domain ($r = 0.72$) also, but showed a significant cross-correlation with the environment domain ($r = 0.44$). This finding may relate to the re-wording of item 15 for the ID *(Is it easy or difficult for you to get around in the house and outside?)* with its more specific reference to internal and external environment, compared with the BREF *(How well are you able to get around?).*

Similarly, item 12 (finance) showed moderate correlation with the predicted domain ($r = 0.54$) on the BREF and did not show significant cross-correlations. However, on the WHOQOL-ID, item 12 showed a relatively higher correlation with the predicted domain ($r = 0.68$) but showed significant cross-correlations with every other domain, including DX.

Once again, this may have related to the slightly different item wording in the two versions of the instrument *(ID: Are you happy or unhappy with the amount of money you have to buy the things you want? BREF: Have you enough money to meet your needs?).* Although, superficially, semantic equivalence appeared to have been preserved in the item re-wording, it is possible that the use of the word 'want' in one version, and 'need' in the other, increased the salience of desires, and 'aspirational' purchasing, for one group (completing the ID) compared with the more basic context of actual need being tapped by the original BREF item.

For item 25 (transport) the correlation with the predicted domain was the lowest achieved on the BREF ($r = 0.42$) and of a completely different order from that demonstrated on the ID version of the instrument ($r = 0.72$). In addition, the pattern of associated domain correlations for this item varied markedly between the two public groups on the different instrument versions. Item 25 did not show cross-correlations with other domains on the BREF, but showed significant cross-correlations with every other domain, including DX, on the ID.

The wording of this item on the two versions of the instrument was very similar *(ID: How happy or unhappy are you with your transport? BREF: How satisfied are you with your transport?)* and thus it may be argued that semantic equivalence was preserved. Yet despite this, two groups of the general public appear to have responded differently to this item in the context of its domain.

Since the two public groups were matched for age, gender and residential locality it might be assumed that their need for, and use of, transport was similar. Although no other (more direct) item on transport use was included as part of the WHOQOL, or in the introductory demographic questions, an item was included in the overall questionnaire pack as part of the Life Experiences Checklist (Ager,

1998). As shown in Table 9.14, the responses to this item seemed to confirm the similar pattern of transport use for the two public groups.

Table 9.14: Use of Transport by General Public Group Participants

LEC item 42: Travel by car or public transport at least once a week

Group	Yes		No	
	N	%	*N*	%
Public – ID	100	97.1	3	2.9
Public – BREF	100	95.2	5	4.8

Missing cases: 0

There may have been other aspects of the characteristics of the two general public subgroups, which explained this finding; alternatively, it may have been scale related. As noted in the previous section on reliability, item 25 (transport) was the one possible problem item flagged for the WHOQOL-BREF, having an item-total correlation below 0.25 (compared with 0.6 on the WHOQOL-ID). However, given the size of the divided public groups and the number of correlations under consideration, it was possible that this was a simple chance finding.

In domain DX, the two matched public groups responded to identical items (exactly as for the ID clients) whichever version of the instrument was completed. Therefore the pattern of significant cross-correlations ($r > 0.4$) would be expected to be similar for both groups. As shown in Table A9.19, there were significant cross-correlations with other domains on all 10 items, of which four were common to both groups.

Six items showed cross-correlations on only one version of the instrument. For the public-BREF, items 27 (stigmatisation), 29 (ridicule) and 34 (advocacy) cross-correlated with the psychological domain, but only just reaching the defined threshold level of 0.4. For the public-ID, item 30 (discrimination) cross-correlated with the environment domain at this threshold level also; item 31 (enabling) loaded on the environment domain; and item 33 (autonomy) loaded on the psychological, social and environment domains, of which the highest level of associated domain correlation was for the environment domain.

Four items showed cross-correlations on both instruments, albeit that the pattern of the associated domain correlations differed between instruments on some items. Item 28 (victimisation) cross-correlated with the environment domain for the public-ID, but with the psychological domain for the public-BREF; item 32 (empowerment) loaded on the psychological, social and environment domains for both the ID and the BREF; item 35 (respect) cross-correlated with the environment domain only for the public-ID, but with the psychological and environment domains for the public-BREF; and item 36 (acceptance) loaded on

the psychological and environment domains for the public-ID, but on the psychological, social and environment domains for the public-BREF.

As noted for the public group overall, these associated domain correlations would be predicted from item content and facet definition, but all these cross-correlations were of a lower order than that for the predicted domain DX, which suggests that these items are placed more appropriately in DX than in the associated domains.

Response Mode (direct and proxy)

Item-domain correlations

As shown in Table A9.20, all items associated with all four base domains (physical, psychological, social and environment) showed the highest correlation with the predicted domain for ID clients in both direct and proxy response mode. However, four items showed relatively lower item-domain correlation ($r < 0.4$) than the other items in the predicted domains: for the direct response mode, item 26 (negative feelings) in the psychological domain and item 9 (physical environment) in the environment domain; and for the proxy mode, item 16 (sleep) in the physical domain and item 6 (spirituality) in the psychological domain.

Item 16 (sleep) showed the lowest correlation with the predicted domain in both direct and proxy mode, and was noted as demonstrating item-domain correlations below 0.4 for both the hospital and community groups overall. Similarly, item 9 (physical environment) showed the lowest correlation with the predicted domain for direct mode and the second lowest for proxy mode. This item demonstrated an item-domain correlation below 0.4 for the community group overall and only just above this level (0.46) for the hospital group. The item-domain correlations for the public group (both overall and by instrument version) were 0.6 or higher on both these items. Taken together, these findings tended to suggest that, for these two items, the impact on item-domain correlation related to the characteristics of intellectually disabled clients irrespective of response mode (even when responses are provided by staff proxies of similar levels of intellectual ability as the general public).

For item 9, as noted in the missing values analysis, there may have been an issue about the extent to which clients understood the concept of a healthy physical environment, either directly, or in the opinion of their proxies. Although, as noted in the reliability analysis, the item-facet correlation of this item reported in the original WHOQOL-100 study was at a similar level (0.36).

For item 16, as noted in the frequencies analysis, it was possible that ID clients' sleep may have been affected by use of medication, such that patterns of positive

responses about satisfaction with sleep may appear inconsistent with patterns of responses on other items in the physical domain.

Item 6 (spirituality) showed the lowest correlation with the predicted domain in the proxy mode, but not in the direct mode. In contrast, item 26 (negative feelings) showed the lowest correlation with the predicted domain in the direct mode, but not in proxy mode. These items were noted in the reliability analysis as possible problem items, particularly at the level of response mode.

For item 6, the issue may have related to the difficulty of capturing the concept of spirituality in an item that could be understood by ID clients, and the impact of this on re-wording and semantic equivalence with the original item. (*BREF item: To what extent do you feel your life to be meaningful? ID item: Is god (or are religious things) important in your life?*). In order to assist item intelligibility, an illustration was provided *(e.g. do you go to Church?)*. However, the presence of this concrete example within the framework of an abstract conceptual item may have opened the way for different response patterns also, by introducing an 'activity' rather than a psychological focus for respondents. In the event, the item may have failed to reflect the original WHOQOL facet and hence may have been interpreted differently by clients and their proxies.

For item 26, although the concept of negative feelings is complex, examples (prompts) were an integral part of the item wording, and the item re-wording appeared to maintain adequate semantic equivalence (*BREF item: How often do you have negative feelings such as blue mood, despair, anxiety, depression? ID item: How often do you feel unhappy, sad or worried?*). Therefore, low correlation with the predicted domain may have been an artefact of the smaller size of the direct response group, particularly as this approached the 0.4 threshold ($r = 0.38$) and was considerably higher than the correlation with any other domain (by a factor >2).

In domain DX, all items showed the highest level of correlation with the predicted domain for ID clients in both direct and proxy response mode, except for item 34 (advocacy) in proxy mode. Item 34 also showed relatively lower item-domain correlations ($r < 0.4$) than the other items in the DX domain for both groups. This may have related to the issue of the relative directional strength of this item for ID clients as noted previously. Clients and staff proxies may have interpreted the 'need' for advocacy in different ways, and as reflecting different values, resulting in a more varied pattern of responses than would be expected of a less ambiguous item.

Cross-correlations

The pattern of item correlation with associated (non-predicted) domains was slightly different for the two response modes. For proxy mode, six items showed significant cross-correlations with other domains (physical, psychological and environment) although having the highest level of correlation with the predicted domain. For direct mode, 15 items demonstrated significant loadings on non-

predicted domains, dispersed throughout the four base domains and DX. Despite the difference in numbers of items showing significant cross-correlations for the two modes (based on the threshold of $r > 0.4$), the trend on the majority of the items in the four base domains was similar for both groups, albeit with more modest domain associations, and similar to the findings for the separate hospital and community groups.

In DX, the pattern of association with non-predicted domains was different for direct and proxy mode. In direct mode, five out of 10 items showed significant cross-correlations with the environment domain: items 28 (victimisation), 32 (empowerment), 33 (autonomy), 35 (respect) and 36 (acceptance). In proxy mode this pattern was not evident on any item.

It appeared that ID clients responding directly to items in the broad thematic categories of social acceptance or inclusion (items 28, 35 and 36) and empowerment (items 32 and 33) did so in such a way that their responses were linked to the response pattern for items in the environment domain i.e. reflecting aspects of their perceptions of their environment.

In contrast, the responses of staff proxies (on behalf of ID clients) appeared to show significant association only with the predicted domain DX.

This finding may have been a function of the differential levels of dependency of those clients having capacity to respond directly, and those requiring staff to answer on their behalf. Alternatively, it might be accounted for in terms of the direct clients' own perceptions of their dependency and related support needs (as the highest item-domain correlations found in the environment domain were for the facets of safety and home), thus indicating a more fundamental difference in how people with intellectual disabilities perceive their world i.e. as individuals typically lacking in autonomy, dependent on others for sustenance and social support, and subject to the vagaries of their living environment.

Response Mode and Research Subgroups

The item-domain correlations for the hospital and community subgroups by response mode and research subgroup are presented in full in Table A.9.21. However, at this level of analysis, the data require to be approached with considerable caution: firstly, in view of the disparity in sample size between the four subgroups; and secondly, in relation to the very small numbers in the direct response subgroups for both hospital patients and community clients.

As shown in Table A.9.21, the overall pattern of item-domain correlations and cross correlations was very similar to that found for the direct and proxy response modes in relation to the combined client groups (presented in Table A.9.20).

Item-domain correlations

For the proxy response mode (with the largest group sizes) all items associated with the four base domains showed the highest correlation with the predicted domain for ID clients in both hospital and community settings. However, four items showed relatively lower item-domain correlations (< 0.4) than other items in the predicted domains: in the physical domain, item 16 (sleep) for both hospital and community proxy groups and item 4 (medication) for the hospital proxy group; in the psychological domain, item 6 (spirituality) for the hospital proxy group; and in the environment domain, item 9 (physical environment) for the community proxy group.

Item 16 (sleep) was flagged with a low item-domain correlation in the overall proxy response mode analysis with the combined ID client groups (Table A9.20) and as shown in Table A9.21, this appeared to be problematic at a similar level in both residential settings. The possible association between the response patterns for this item and prescribed hypnotic or psychotropic medication, initially suggested in relation to the frequency analysis, might explain the different order of this item-domain correlation. As shown in Table 9.15, the pattern of reported use of medication was similar in direct and proxy response conditions and proportionate to that for the hospital and community groups overall.

Table 9.15: Hospital and Community Group Direct and Proxy Participants Use of Medication/Medical Treatment (item 4)

Use of medication / medical treatment	Hospital			Community		
	Direct	Proxy	Total	Direct	Proxy	Total
	%	%	%	%	%	%
Little or none	39.2	31.9	32.9	30.4	32.9	32.4
Moderate or greater	60.8	68.1	67.1	69.6	67.1	67.6
	(*N*=28)	(*N*=185)	(*N*=213)	(*N*=46)	(*N*=158)	(*N*=204)

Missing cases: 0

For item 4 (medication) a low item-domain correlation was not found in relation to proxy mode for the combined client groups, but was evident for the hospital-proxy group in contrast to the community-proxy group. However, given the similar pattern of use of medication/medical treatment as shown in Table 9.15, this may be a chance finding, or may be linked to the specific characteristics of the hospital staff responding on behalf of hospital clients. For example, the aggregate data for moderate or greater use of medication, compared with little or no use, masks the hospital proxies tendency to rate clients' need for medication at response scale point 4 *(quite a lot)* or 5 *(a great deal)* more frequently than community proxies, as shown in Table A.9.12.

Item 6 (spirituality) was flagged with a low item-domain correlation in the overall proxy response mode analysis with the combined ID client groups (Table A9.20). However, as shown in Table A9.21, the low item-domain correlation was most evident in the hospital proxy group ($r = 0.27$). As noted in the earlier section, this may have been associated with the difficulty of capturing the concept of spirituality in an intelligible item, and reflected a failure to match the re-worded item to the definition of the facet within the overall domain.

However, half of the general public group responded to the ID version of item 6 also. As shown in Table 9.16 and Figure 9.23, this sample of the public were divided equally between those who rated God or religion as of little or no importance, and those rating such spiritual matters as of moderate or greater importance. In contrast, the ratio for the community group was closer to 86:14 and for the hospital group was 93:7.

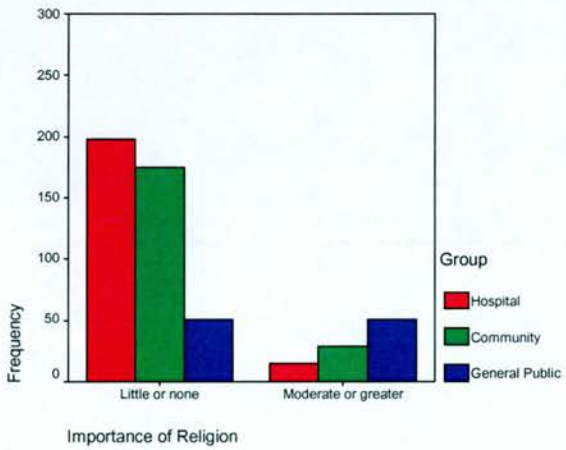
Table 9.16: Research Group Responses for WHOQOL-ID Item 6 (spirituality)

Importance of god or religion	General Public	Hospital	Community
	%	%	%
Little or none	50.0	93.0	85.8
Moderate or greater	50.0	7.0	14.2
	(*N*=103)	(*N*=213)	(*N*=204)

Missing cases: General public = 1

This suggested that spiritual matters (as defined by the ID wording of item 6) were less important to ID clients in the community and in hospital than to the general public. A 3*2 chi-square was carried out to test the relationship between subject group and tendency to rate religion as of low importance. This confirmed a significant difference between the groups ($\chi^2 = 88.871$, $df = 2$, $p < 0.001$).

Figure 9.23: Research Group Ratings for Item 6 (spirituality)



As figure 9.23 demonstrates clearly, both hospital patients and community clients were significantly more likely to rate religion as of low importance compared with the general public.

However, as shown in Table 9.17, when the responses of the hospital and community groups were analysed by response mode, it was evident that approximately one third of clients responding directly rated God or religion as of moderate or greater importance in both groups, compared with less than 8% in both proxy groups.

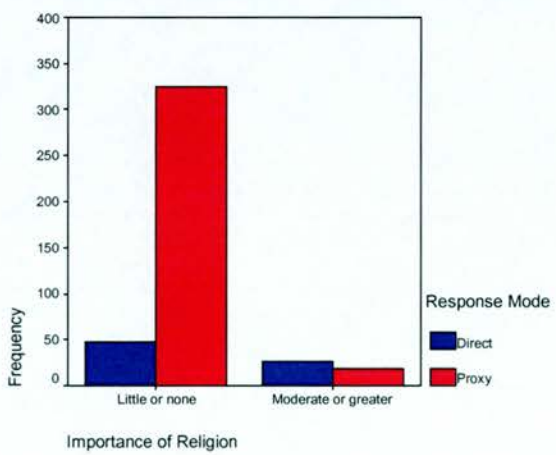
Table 9.17: Response Mode Responses for WHOQOL-ID Item 6 (spirituality)

Importance of god or religion	Hospital		Community	
	Direct	Proxy	Direct	Proxy
	%	%	%	%
Little or none	67.9	96.8	63.0	92.4
Moderate or greater	32.1	3.2	37.0	7.6
	(*N*=28)	(*N*=185)	(*N*=46)	(*N*=158)

Missing cases: 0

This finding suggested that clients responding directly approached the public response pattern much more closely than did staff responding on clients' behalf. Initially, a 4*2 chi-square was carried out to test the relationship between response mode and tendency to rate religion as of low importance. However, as some cells were found to have low expected frequencies (25% of cells with expected counts < 5) the chi-square statistic was likely to be an overestimate and therefore unreliable. Therefore, the cells for the two direct sub groups and the two proxy sub groups were combined to produce a 2*2 contingency table and a further chi-square test was performed to compare direct response mode with proxy response mode for the combined client groups.

Figure 9.24: Response Mode Ratings for Item 6 (spirituality)



In this format, the minimum expected count was 7.8, which was satisfactory for the chi-square test. However, since this lowest expected frequency was still < 10, Yates correction was applied. This confirmed a significant difference between the direct and proxy groups ($\chi^2 = 54.484$, $df = 1$, $p < 0.001$).

As figure 9.24 demonstrates, the proxy staff responding on clients' behalf were significantly more likely to rate religion as of low importance compared with clients responding directly themselves.

The overall response pattern for this item may reflect actual differences between the importance of God or religion linked to the characteristics of ID clients (e.g. functional ability or dependency linked to response mode). However, there may be an alternative (or additional) effect linked to downward social comparisons (Festinger, 1954) made by staff proxies based on their perceptions of clients' capacity to relate to the construct of religion, which can present difficulties for individuals without intellectual disabilities.

Item 9 (physical environment) was flagged with a low item-domain correlation in the overall direct response mode analysis with the combined ID client groups (Table A9.20). However, as shown in Table A9.21, a low item-domain correlation was found in respect of the community proxy group ($r = 0.28$) as well as for both direct subgroups. As noted previously, this finding may reflect issues of conceptual intelligibility, or may echo the relatively lower item-domain correlation found for this item in the original WHOQOL study.

For the direct mode, the majority of items associated with the four base domains showed the highest correlation with the predicated domain for ID clients in both hospital and community settings. However, for the hospital-direct group, the exceptions were item 16 (sleep) which had higher correlations with the psychological and social ($r = 0.64$) domains than with the predicted physical domain; item 5 (positive feelings) which had higher correlations with the social and environment domains than with the predicted psychological domain; item 12 (finance) which had a higher correlation with DX ($r = 0.65$) than with the predicted environment domain; and item 23 (home) which had equivalent item-domain correlations ($r = 0.61$) on both the predicted environment domain and on the social domain. For the community-direct group, the exceptions were item 18 (work) which had higher correlations with the psychological and environment domains than with the predicted physical domain; and item 26 (negative feelings) which had a higher correlation DX than with the predicted psychological domain. In addition, four items showed relatively lower item-domain correlations (< 0.4) than other items in the predicted domains: item 26 (negative feelings), item 12 (finance) and item 14 (leisure activities) for the hospital-direct group; and item 9 (physical environment) for both hospital-direct and community-direct groups.

In domain DX, for the two proxy response groups, all items showed the highest level of correlation with the predicted domain except for item 34 (advocacy) in relation to the hospital-proxy group (for which item-domain correlations for advocacy were low to negligible across all five domains). For the community-proxy group, item 34 showed a relatively lower item-domain correlation (< 0.4) than other items in the predicted domain also. Item 34 was flagged with a low item-domain correlation in the overall proxy response mode analysis with the combined ID client groups also (Table A9.20).

For the hospital-direct group, all items in DX showed the highest level of correlation with the predicted domain except for item 27 (stigmatisation) and item 34 (advocacy) which had higher negative correlations with the psychological domain, but all of which were <0.3; and item 35 (respect) which had equivalent positive item-domain correlations ($r = 0.51$) on both the predicted DX and on the environment domain. For the community-direct group, all items in DX showed the highest level of correlation with the predicted domain except for item 33 (autonomy) which had higher correlations with every other domain, the highest of which was with the physical domain ($r = 0.50$); and item 34 (advocacy) which had very small to marginal correlations with all domains. In addition, item 31 (enabling) showed a relatively lower item-domain correlation (< 0.4) than other items in the predicted domains for the community-direct group.

Given the small size of the hospital-direct and community-direct response mode subgroups, it was not possible to extrapolate reliably from these findings.

Cross-correlations

The pattern of item correlation with associated (non-predicted) domains was similar to that found for the combined client group by response mode (Table A9.20), being slightly different for the proxy and direct response modes, but similar for both hospital and community subgroups.

As shown in Table A9.21, for proxy mode, six items showed significant cross-correlations with three of the base domains (physical, psychological and social) although having the highest level of correlation with the predicted domain. Five of these were common to both hospital-proxy and community-proxy groups. In addition, item 23 (home, environment domain) showed significant cross correlations (>0.4) with the psychological and social domains for the community-proxy group, but not for the hospital-proxy group; and item 32 (empowerment, DX) showed significant cross correlations with the physical and environment domains for the community-proxy group, but not for the hospital-proxy group. These two findings seemed to suggest that, for community clients, proxy staff were identifying a link between psychosocial well-being and aspects of 'home'; and an even stronger link between physical capacity, environment and the impact of 'empowerment'.

For direct mode, 23 items demonstrated significant loadings on non-predicted domains, dispersed throughout the four base domains and DX. Ten of these were common to both hospital-direct and community-direct groups; seven related to the hospital-direct group only; and six related to the community-direct group only.

In DX, the pattern of association with non-predicted domains was different for direct and proxy groups. For the hospital-direct mode, four items showed significant cross-correlations with the environment domain: items 32 (empowerment), 33 (autonomy), 35 (respect) and 36 (acceptance). For the community-direct mode, three items showed significant cross-correlations with the environment domain: items 28 (victimisation), 30 (discrimination) and 36 (acceptance). In proxy mode, this pattern was only evident for item 32 (empowerment) for the community-proxy group. Therefore, the suggestion of a response pattern link between aspects of environment and social acceptance for the combined client group in direct response mode seemed to be borne out in the separate hospital and community direct groups also, but was not reflected in the responses of proxy staff for either group.

Summary of Stage One of Correlation Analysis

Overall, stage one of the correlation analysis confirmed that all items in the base domains, and nine out of ten items in DX, tended to have the highest correlations with the predicted domain. This replicated the findings from the original WHOQOL study in relation to the base items, and suggested that nine of the new items represented additional quality of life themes and were not tapping facets already included in the scale.

The one exception to this was item 34 (advocacy) in DX, which showed higher correlations with non-predicted domains and/or low correlations with the predicted DX domain across a number of levels of analysis.

However, the findings for item 34 remain somewhat ambiguous. The current data suggested that the item was problematic and lacking in reliability for intellectually disabled persons, but in connection with the general public group the item showed moderate level correlations with the predicted domain and appeared appropriately placed in DX. Inter-alia the correlation analysis provided additional support for dropping item 34 from the scale in its present format, but this facet may be worthy of reconsideration (comparing the impact of a number of alternatively worded items) in a future study.

A varying number of significant item-domain cross-correlations were found at different levels of analysis, but the relationship between these items and their predicted and associated domains was either explicable or predictable in terms of item content, facet definition or the characteristics of the study participants.

In terms of the new items, the most significant finding related to the response mode data, which suggested that ID clients responding directly demonstrated a similar response pattern to some of the items in the broad thematic categories of social inclusion and empowerment (domain DX) as for items in the environment domain.

9.4.2 Domain DX and Sub Domain Variations

The correlations for the originally hypothesised single domain DX were compared with those for the alternative two-domain structure DY and DZ across the six levels of analysis and the results are presented in full in Tables A9.22 - A9.25 in Appendix 9.

This stage of the correlation analysis was informed by the reliability findings, and hence the pattern correlations for the ten-item DX was examined together with a six-item configuration of DY (comprising items 27, 28, 29, 35 and 36) and both a four-item configuration of DZ (comprising items 31, 32, 33 and 34) and a comparative three-item DZ (minus item 34, advocacy) in order to identify the configuration which produced the highest item-domain loadings.

Item-domain correlations

As shown in Tables A9.22 – A.9.25, the results of this correlation analysis suggested that the two-domain structure of DY and DZ (2) produced the superior item-domain correlations across the levels of analysis. This trend was clearest and most consistent in the larger groups (total group, hospital group, community group, public group, proxy response mode) but was evident also in the smaller subgroups (e.g. direct response mode).

For each configuration, the number of items showing the highest correlation with that domain is summarised in Table 9.18. As this shows, one or two out of the 10 items correlated highest with domain DX and mostly within the smaller groupings. These highest correlations with DX involved three items only: item 36 (acceptance) for the community, community proxy and the direct response mode groups; item 35 (respect) for the direct response group overall, for the community-direct subgroup, and for the public BREF subgroup (but not for the public ID subgroup, despite exactly the same wording for these 10 items on each version of the instrument); and item 27 (stigmatisation) for the hospital-direct subgroup.

In contrast, the majority of the six items had the highest item-domain correlation with domain DY across all groupings (six out of six in seven groups, five in three groups and four in three of the smallest groups); and the other four items had the highest correlation with domain DZ across all groupings.

Table 9.18: Summary of Item-Domain Correlations for DX, DY and DZ

Analysis Level	Group	*N*	No. of Items with Highest Correlation				Item Exceptions	
			DX 10 items	DY 6 items	DZ (1) 4 items	DZ (2) 3 items	DX	DZ (1)
Total Group	All Subjects	625		6	1	3		34
Research Groups	Hospital	213		6		3		
	Community	204	1	5	1	3	36	34
	General Public	208		6	1	3		34
WHOQOL Versions	ID Clients & Public	520		6	1	3		34
	ID Public	103		6	1	3		34
	BREF Public	105	1	5	1	3	35	34
Response Mode	Direct	74	2	4	1	3	35, 36	34
	Proxy	343		6	1	3		34
Response Mode & Research Group	Hospital-Direct	28	2	4	1	3	27, 36	34
	Community-Direct	46	2	4	2	2	35, 36	33, 34 *
	Hospital-Proxy	185		6	1	3		34 *
	Community-Proxy	158	1	5	1	3	36	34

* Item-domain correlation < 0.4 Blue: All items have highest correlation with domain

However, configuration DZ (2) produced the superior pattern of item-domain correlations overall compared with DZ (1). All three items correlated highest with domain DZ (2) in 12 groups, and two out of three items correlated highest with DZ (2) in one small group. The consistent exception was item 34 (advocacy), which had the highest correlation with DZ (1) in 12 groups, although this correlation fell below 0.4 in two of these groups.

Cross-correlations

The pattern of significant cross-correlations (as defined by $r > 0.4$) for the superior configuration of DY and DZ (2) was inspected to determine the inter-relationship between the two domains.

As shown in Table A9.22, for the total group only items 35 (respect) and 36 (acceptance) showed significant cross-correlations with DZ (2), although having the highest correlation with the predicted DY. However, as the set of Tables A9.22 - A9.25 show, the total group picture masked broad differences in findings for ID clients compared with the general public.

A summary of the significant cross-correlations with non-predicted domains for the range of ID client groups by level of analysis is presented in Table 9.19. As this shows, for the ID clients groups, significant cross-correlations with non-predicted domains were noted for three items: item 32 (empowerment) on DY; and items 35 (respect) and 36 (acceptance) on DZ (2), predominantly in respect of community clients and direct response mode.

Table 9.19: Summary of Cross-Correlations for ID Clients

			Cross-correlations		
Analysis Level	Group	*N*	Item 32	Item 35	Item 36
Research Group	Hospital	213			
	Community	204	X		X
Response Mode	Direct	74	X	X	X
	Proxy	343			
Response Mode	Hospital-Direct	28			X
& Research Group	Community-Direct	46	X	X	X
	Hospital-Proxy	185			
	Community-Proxy	158	X		

X: denotes cross-correlation > 0.4 with non-predicted domain

For the general public groups, significant cross-correlations with non-predicted domains were noted for eight out of nine items: items 31 (enabling), 32 (empowerment) and 33 (autonomy) on DY; and items 28 (victimisation), 29 (ridicule), 30 (discrimination), 35 (respect) and 36 (acceptance) on DZ (2).

A summary of these significant cross loadings with the non-predicted domain for the range of general public groups by level of analysis is presented in Table 9.20. This shows that the overall pattern of cross-correlations for the general public was relatively consistent across the combined public group and the WHOQOL version subgroups.

Table 9.20: Summary of Cross-Correlations for General Public

			Cross-correlations to DY			Cross-correlations to DZ (2)				
Analysis Level	Group	*N*	Item 31	Item 32	Item 33	Item 28	Item 29	Item 30	Item 35	Item 36
Research Group	General Public	208	X	X	X	X		X	X	X
WHOQOL Version	Public - ID	103	X	X	X	X		X	X	X
	Public - BREF	105	X	X	X	X	X		X	X

X: Denotes cross-correlation > 0.4 with non-predicted domain

The relationship between these new items and their predicted and associated domains was explicable and predictable given the nature of the items and related facets (originally conceptualised as a single domain). The more interesting finding was the overall differences between the ID clients and the public (although some item association trends were present for all groups at lower non-significant levels).

The differences cannot be attributed to item wording, or problems with semantic equivalence, as the items had identical wording on both the ID and BREF versions of the instrument. Therefore, the variation in extent of item cross-correlations may have been linked to differences in the characteristics of the groups of study participants, or differences in their perceptions of, or actual experience of, social exclusion/inclusion and personal empowerment.

The response frequency data on these items for the ID clients and the public provided some support for such an explanation linked to differential experience.

Using the raw data (not recoded) for the three 'reversed' social inclusion items (28, 29 and 30) on which high scores contributed to poorer quality of life, the percentage of responses at the upper three points of the response scale (3-5) and lower scale points (1-2) for the client and public groups are shown in Table 9.21. Although the absolute level of 'high' frequency reporting was relatively modest in percentage terms, overall these data suggested that hospital patients and community clients (or their proxies) were more likely to report experience of discrimination and other aspects of social *ex*clusion than the public, even though the community clients and the public resided in the same neighbourhoods.

Table 9.21: Upper and Lower Scale Point Frequencies for Social Exclusion Items

Item	Facet	Hospital		Community		General Public	
		High	Low	High	Low	High	Low
		%	%	%	%	%	%
28	Victimisation	34.3	65.7	33.8	66.2	18.8	81.2
29	Ridicule	20.2	79.8	13.7	86.3	6.3	93.8
30	Discrimination	21.1	78.9	28.9	71.1	6.7	93.3
		(*N* = 213)		(*N* = 204)		(*N* = 208)	

Missing cases: general public group = 3 for items 28, 29; and = 4 for item 30

A series of 3*2 chi-square tests on the aggregated response frequencies for these three items confirmed significant differences between the groups. As shown in Figure 9.25, ID patients and clients made more frequent reports of 'high' levels of victimisation ($\chi^2 = 15.807$, $df = 2$, $p < 0.001$); 'high' levels of ridicule ($\chi^2 = 17.594$, $df = 2$, $p < 0.001$); and 'high' levels of discrimination ($\chi^2 = 34.179$, $df = 2$, $p < 0.001$) than members of the public.

For the remaining two social inclusion items (35 and 36) on which low scores contributed to poorer quality of life, the percentage of responses at the lower three points of the response scale (1-3) and upper scale points (4-5) for the client and public groups are shown in Table 9.22. Once again, the absolute level of (in this case) 'low' frequency reporting was relatively modest in percentage terms, however these data suggested that hospital patients and community clients (or their proxies) were more likely to report lower levels of social *in*clusion than the public.

Table 9.22: Upper and Lower Scale Point Frequencies for Social Inclusion Items

Item	Facet	Hospital		Community		General Public	
		High	Low	High	Low	High	Low
		%	%	%	%	%	%
35	Respect	57.3	42.7	70.1	29.9	77.4	22.6
36	Acceptance	83.6	16.4	82.4	17.6	91.8	8.2
		(*N* = 213)		(*N* = 204)		(*N* = 208)	

Missing cases: general public group = 2 for item 36; and = 3 for item 35

3*2 chi-square tests on the aggregated response frequencies for these two items confirmed significant differences between the groups. As shown in Figure 9.26, ID patients and clients made more frequent reports of 'low' levels respect (χ^2 = 20.167, df = 2, $p < 0.001$) and 'low' levels of acceptance (χ^2 = 9.119, df = 2, p = 0.01) compared with members of the public.

For the three empowerment items (items 31, 23 and 33) on which low scores contributed to poorer quality of life, the percentage of responses at the lower three points of the response scale (1-3) and upper scale points (4-5) for the client and public groups are shown in Table 9.23.

Table 9.23: Upper and Lower Scale Point Frequencies for Personal Empowerment Items

Item	Facet	Hospital		Community		General Public	
		High	Low	High	Low	High	Low
		%	%	%	%	%	%
31	Enabling	65.3	34.7	73.0	27.0	83.2	16.8
32	Empowerment	74.6	25.4	85.8	14.2	73.1	26.9
33	Autonomy	58.7	41.3	77.0	23.0	71.0	22.1
		(*N* = 213)		(*N* = 204)		(*N* = 208)	

Missing cases: general public group = 2 for item 32; and = 3 for items 31 and 33

3*2 chi-square tests on the aggregated response frequencies for these three items revealed significant differences also. However, as shown in Figure 9.27, the picture that emerged was more mixed. ID patients and clients made more frequent reports of 'low' levels of enabling compared with the public (χ^2 = 17.532, df = 2, $p < 0.001$); and hospital patients made more reports of 'low' autonomy (χ^2 = 24.015, df = 2, $p < 0.001$) than either of the other two groups; but for this dataset, community clients reported superior levels of 'high' empowerment (χ^2 = 11.426, df = 2, $p < 0.01$) compared with the other two groups. This may have been an artefact of the recent transition of these clients to community settings and the related investment of care staff in establishing the success of the resettlement programme for individuals.

Figure 9.25: Response Frequencies for Social Exclusion Items by Research Group

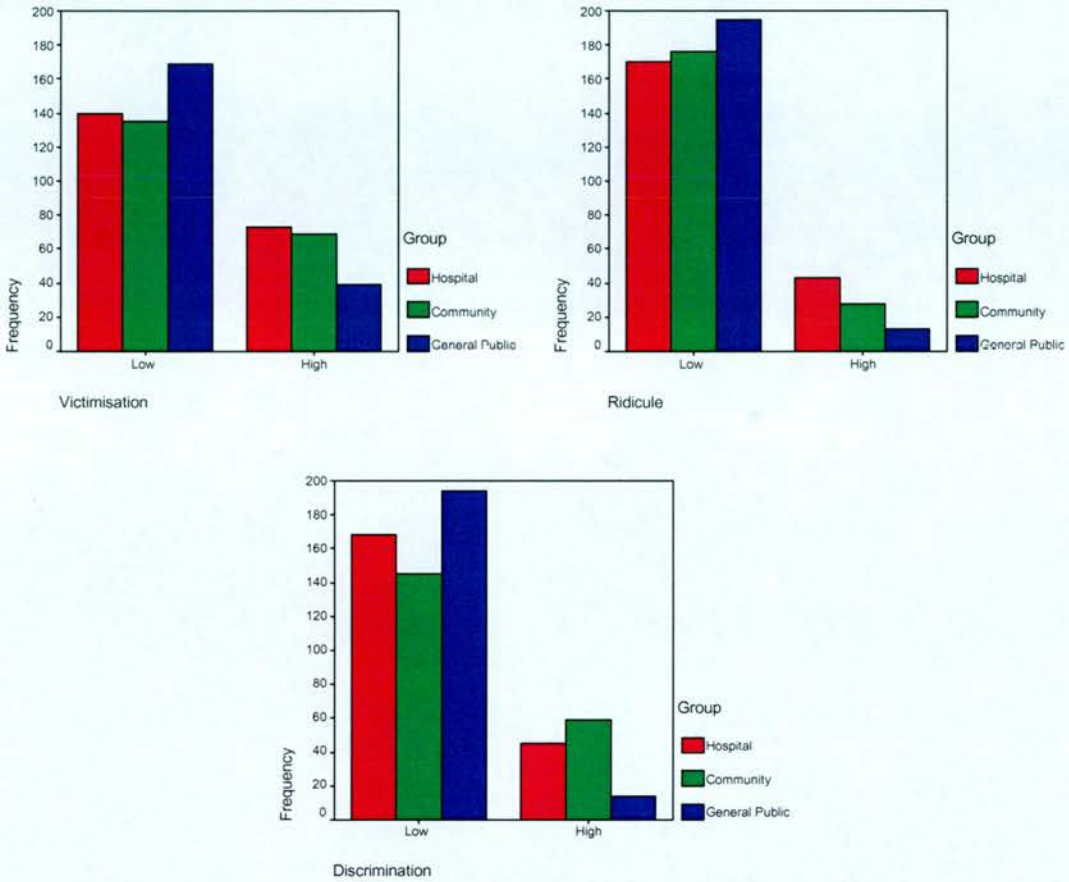


Figure 9.26: Response Frequencies for Social Inclusion Items by Research Group

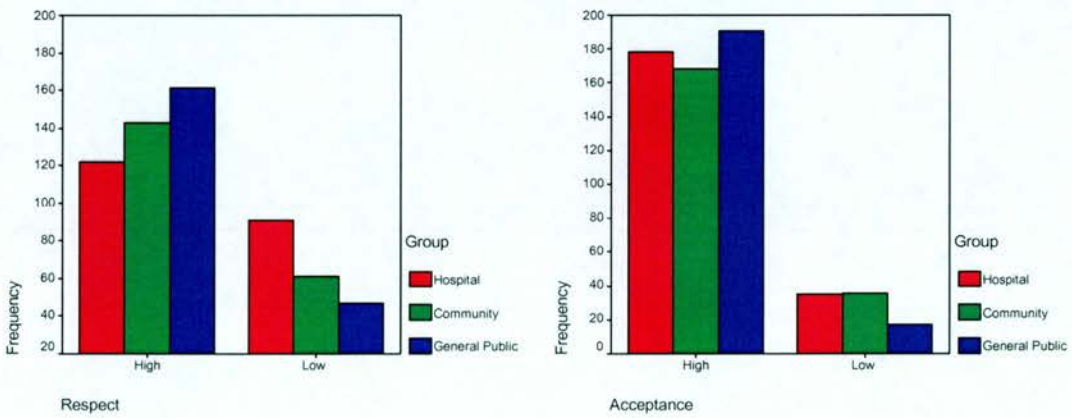
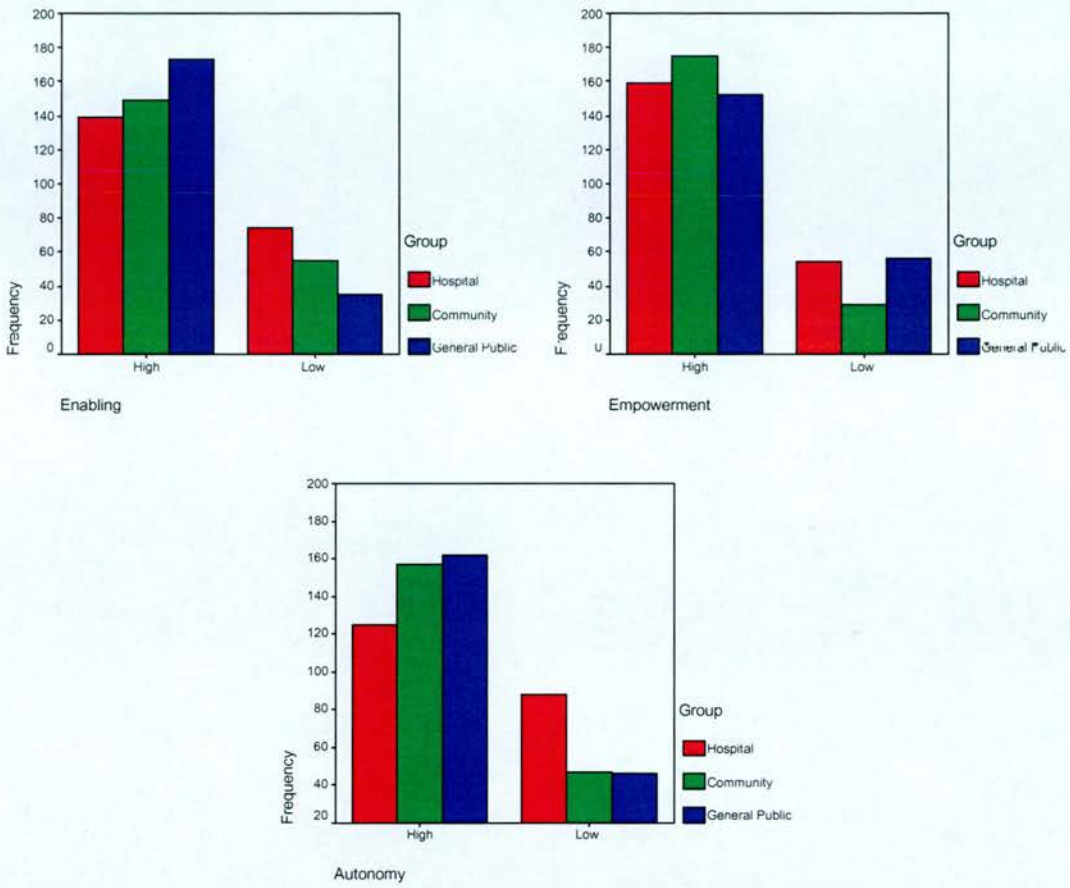


Figure 9.27: Response Frequencies for Empowerment Items by Research Group



Overall, the statistics confirmed the trend for people with intellectual disabilities to experience less social inclusion and less personal control of their lives compared with the public. Although the relationship between these facets of quality of life is apparent for the public group, paradoxically, this seemed to be evident only at lower levels for the client groups, despite their greater social disadvantage.

Summary of Stage Two of Correlation Analysis

Stage two of the correlation analysis demonstrated that superior item-domain correlations were achieved by a two-domain structure for the new items based on a six-item DY and a three-item DZ, compared with the original DX domain (in nine or 10-item format). This confirmed the findings of the reliability analysis.

In this configuration, a number of significant item-domain cross-correlations were noted, but the relationship between these items and their predicted and

associated domain was consistent with the thematic content and wording of items.

In addition, there was evidence to suggest that some of the variation in cross loadings found for the ID client and public groups may have reflected differential experience of social inclusion and individual empowerment. This may be linked to the impact of intellectual disabilities (and associated impairments) directly i.e. the characteristics of clients, or the perceptions of these by proxy respondents, or may have related to wider contextual issues such as low social valuation and historical segregation.

9.5 Factor Analysis

Following the reliability and correlation analyses, the inter-relationship of the 33 items remaining in the WHOQOL-ID was explored, and the underlying structure was examined to determine the nature of the higher order factors or latent variables. The objective of this aspect of the psychometric analysis was to compare the resultant factor structure, and the related predictor variables, to the four-domain structure reported for the WHOQOL-BREF (WHOQOL Group, 1998a).

In the original WHOQOL methodology, exploratory factor analysis was performed on a random split half of the sample, and confirmatory factor analysis was carried out on the other random split half of the subjects. This approach allows the structure of an instrument to be explored with one half of the subject group, and the resultant model to be tested against other models (including those derived from theory and previous research) with the other half of the group. The divided sample method prevents overestimation of fit of the model derived from the exploratory factor analysis, as a separate dataset is available to test the models (Kline, 1994; Bryant and Yarnold, 1998).

However, this approach requires a large dataset in order for the split halves to meet the sample size requirements for both the exploratory and confirmatory statistical procedures. In the original WHOQOL-100 study, the total subject group was very large, providing split half samples of over 2,000 subjects. In the present study, the 'natural' dataset for factor analysis of the WHOQOL-ID was the combined group of clients ($N = 417$) from hospital and community settings. This group would have provided random split half samples only one tenth of the size at just over 200 subjects.

For both exploratory and confirmatory factor analysis, large samples are required. In this context, various recommendations have been made about the minimum sample size to produce reliable factors and test models, but the general approach is 'the more subjects the better' (Kline, 1994). For example, Tabachnick and Fidell (2001) recommend a *minimum* of 300 subjects for both exploratory and confirmatory factor analysis, linked to the ratio of subjects to

variables for exploratory analysis, and subjects to estimated parameters for confirmatory analysis.

A range of subject to variable ratios have been suggested as the minimum requirement for exploratory analysis, but a typical recommendation is 5-10 times as many subjects as measured variables (Bryant and Yarnold, 1998). For the current study, setting the subject to variable ratio at 10:1 for the exploratory factor analysis would have required 330 subjects (in the context of the 'all item' set of 33 variables) implying the need for a total group of 660 subjects.

However, for confirmatory factor analysis (using the maximum likelihood method) it has been suggested that a subject to variable ratio of 20:1 is required in order to avoid chance effects (Nunnally, 1978). This would have required a split half sample of 660 subjects, implying the need for a total group of over 1,300 subjects. A similar sample size requirement would be derived from the alternative approach based on a subject to estimated parameter ratio of 10:1 (Hair et al, 1998) which would have produced a split half sample requirement in excess of 600 (on the basis of 33 variables with associated error terms).

The issue of sample size is particularly important in relation to confirmatory factor analysis, as smaller samples are prone to Type I error (failure to detect a model's true lack of fit) as the indices of goodness of fit may be inflated as a result of low statistical power (Bryant and Yarnold, 1998). Therefore, whilst exploratory factor analysis could have been performed on one random half of the combined client group (c.200 subjects) meeting the lowest criterion of at least 5 subjects to each variable, confirmatory factor analysis could not have proceeded reliably with the other random half as this would not have met either the subject to variable or the subject to estimated parameter ratios required for model testing.

The overall dataset for the factor analysis could have been expanded marginally by including the half of the general public group (103 people) who completed the WHOQOL-ID version of the instrument. The inclusion of these participants would have increased the potential sample size to 520 subjects. However, the resultant divided samples of 260 subjects would still have failed to meet the minimum requirements for the split half design. Also, the advantages of heterogeneity in this combination of subjects (increasing the variance) was outweighed by the fact that such a sample was not a reflection of a 'real population' as the public would not be included within the target group for the final adapted instrument.

Within the parameters of the current study, the alternative means of increasing the sample size i.e. the recruitment and assessment of additional subjects was not an option, since the (already quite large) cohort of people with intellectual disabilities in both the hospital and community settings was at the maximum available in terms of geographical boundaries and related ethical approvals.

The problematic methodological choice seemed to be:

(i) Conduct exploratory factor analysis only, on the combined client dataset of 417 subjects, with the inherent design limitation of no testing of resultant models;

(ii) Carry out both exploratory and confirmatory factor analysis on small split half samples from the combined client group, but with the divided samples meeting neither the size requirement for extracting reliable factors, nor that for producing satisfactory tests of models; or

(iii) Perform both stages of factor analysis sequentially on the combined client dataset, but with the design implication of the potential for overestimation of fit in relation to any model generated from the exploratory factor analysis, as a result of testing it on the data from which it was derived.

However, prior to the exploratory factor analysis, it was not clear whether the factor structure of the WHOQOL-ID would be similar to, or different from, that of the WHOQOL-BREF from which it was adapted. If the underlying factor structure of the 24 base items was the same, then the findings of the original WHOQOL study would be replicated with a different client group. The requirement for confirmatory factor analysis would still remain, but could be performed in the context of a much larger (preferably cross cultural) study to refine the instrument. If the underlying factor structure of the base items was different, then for this item set the existing WHOQOL model could be tested appropriately on the new ID client data (on the basis of the combined group of 417 clients) albeit with appropriate caution in relation to a dataset slightly smaller than desirable, but of sufficient size to be just feasible.

On this basis, with appropriate caution, and in order to allow a fuller exploration of the WHOQOL-ID in the current study, the factor analysis procedures were conducted on the combined ID client group.

9.5.1 Exploratory Factor Analysis

In line with the original WHOQOL methodology, exploratory factor analysis using the principal components extraction method with varimax rotation was carried out using SPSS (Windows) Version 11. Orthogonal rotation was employed (as in the original study) to simplify the structure while maintaining the assumption of uncorrelated factors.

The dataset for the exploratory factor analysis was the combined group of clients ($N = 417$) from hospital and community settings. This provided an appropriate subject to variable ratio, for all three levels of analysis at just over 12:1 for the 'all item' set of 33 variables, and a more than adequate subject to expected factor

ratio of over 60:1 (based on a 10:1 and 20:1 minimum respectively, see Kline, 1994).

Three separate analyses of the overall set of 33 items were performed:

1 *New items only:* the subset of 9 new items that represented the additional facets or themes of quality of life that had been found to be relevant for people with intellectual disabilities (items 27–36, but excluding item 34 which had been found to have poor reliability).

2 *Base items only:* the subset of 24 items that were the re-worded items reflecting the facets contained in the original WHOQOL-BREF (items 3-26, excluding general items 1 and 2).

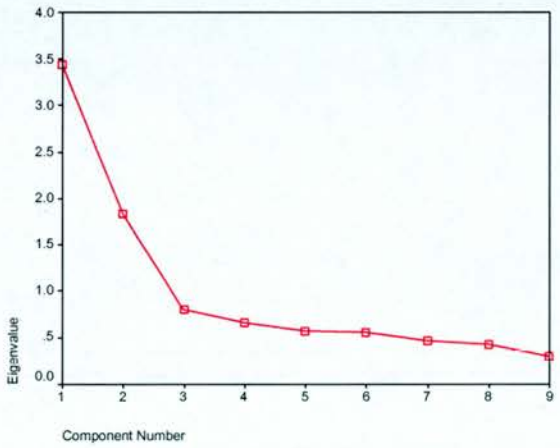
3 *All items:* the total set of 33 items contained in the full WHOQOL-ID (items 3-36, excluding general items 1 and 2, and item 34).

These three levels of analysis allowed direct comparison to be made between the structure of the WHOQOL-BREF and WHOQOL-ID in terms of the parallel set of 24 items; and for the 9 new items to be examined both separately and in relation to the impact on the full 33-item WHOQOL-ID.

New items

For the subset of nine new items, the principal components analysis yielded two factors with eigenvalues greater than one, explaining 58.6% of the variance.

Figure 9.28: EFA Scree Plot for New WHOQOL-ID Items



As figure 9.28 shows, the scree plot of factors suggested that this solution was appropriate; and it was consistent with the conceptual model introduced previously in Table 9.12 in the summary of stage two of the reliability analysis.

The results of the rotated two-factor solution (showing significant loadings >0.4) are presented in Table 9.24. The first factor included negative facets such as ridicule and discrimination, along with positive facets such as respect, suggesting that this might represent a 'social inclusion' domain. The second factor included facets broadly reflecting support and independence, which might represent a 'personal empowerment' domain. The facets of respect and acceptance cross-loaded on this second factor, suggesting that these aspects of social inclusion were associated positively with independence and empowerment also.

Table 9.24: Principal Components Analysis of New Items

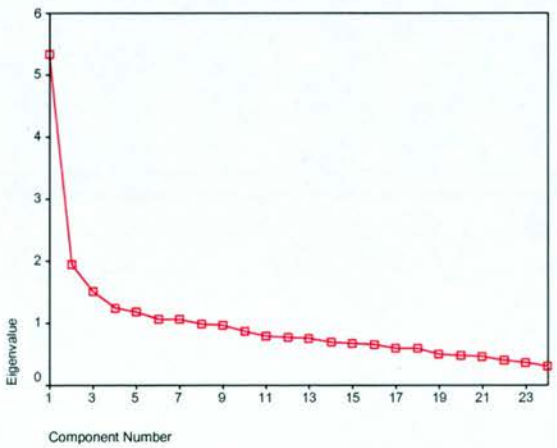
Item	*Facet*	*Factor 1*	*Factor 2*
29	Ridicule	0.83	
28	Victimisation	0.77	
27	Stigmatisation	0.77	
30	Discrimination	0.74	
35	Respect	0.50	0.47
36	Acceptance	0.46	0.45
32	Empowerment		0.82
31	Enabling		0.79
33	Autonomy		0.76

All Clients - Combined Hospital and Community Groups ($N = 417$)

Base Items

For the subset of 24 base items, the principal components analysis yielded seven factors with eigenvalues greater than one, explaining 55.4% of the variance. However, both the sixth and seventh factors comprised two items only.

Figure 9.29: EFA Scree Plot for Base Items



The WHOQOL Group reported alternative four-domain and six-domain solutions for the WHOQOL-100, and a four-domain solution for the shorter WHOQOL-BREF. As figure 9.29 shows, the scree plot of factors in the current study suggested that a four or five domain solution might provide the best fit for the current dataset, depending on interpretation of the scree drop test.

The four-factor solution explained 41.7% of the variance, compared with 46.6% for the five-factor solution.

In order to facilitate comparison with the BREF model, the results of the rotated four-factor solution (showing significant primary factor loadings >0.3 and secondary factor loadings >0.4) are presented in Table 9.25. The results of the five-factor solution are presented in Table A9.26 in Appendix 9 for comparison.

Table 9.25: Principal Components Analysis of Base Items (4-factor solution)

Item	*Facet*	*Factor 1*	*Factor 2*	*Factor 3*	*Factor 4*
23	Home	0.78			
20	Personal relationships	0.67			
24	Health/social care	0.65			
8	Safety	0.62			
22	Social support	0.62			
5	Positive feelings	0.54	0.42		
19	Self esteem	0.50	0.46		
12	Finance	0.37			
9	Physical environment	0.30			
17	ADL		0.73		
10	Energy		0.68		
18	Work		0.66		
11	Body image		0.56		
15	Mobility		0.49		
7	Thinking		0.37		
16	Sleep		0.37		
13	Information			0.62	
14	Leisure activities			0.60	
25	Transport			0.49	
6	Spirituality			0.45	
3	Pain				0.61
4	Medication				0.54
21	Special relationship	0.44			-0.47
26	Negative feelings				0.40

All Clients - Combined Hospital and Community Groups ($N = 417$)

As shown in Table 9.25, the underlying structure of the re-worded base set of items in the WHOQOL-ID appeared to differ considerably from that established for the original WHOQOL-BREF.

The first factor included a cluster of facets related to home, personal relationships, safety, social support and positive feelings, suggesting that this might represent a domain of 'social and emotional care and support'. This first factor explained almost one quarter of the variance (22.2%) with all other factors accounting for 8% or less. The highest loading facet on the first factor was home (>0.7), with four other facets loading >0.6 (personal relationships, health/social care, safety and social support) and two further facets loading ≥0.5 (positive feelings and self esteem). In the original WHOQOL-100 and WHOQOL-BREF these seven facets loaded on the psychological domain (2 items), social domain (2 items) and environment domain (3 items).

The second factor comprised a group of facets broadly related to physical and psychological capacity, which might represent a domain of 'functional ability'. The highest loading facet on the second factor was activities of daily life (>0.7), with two other facets loading >0.6 (energy and work), and two further facets loading ≥0.5 (body image and mobility). In the original WHOQOL-100 and WHOQOL-BREF these facets loaded on the physical domain (4 items) and psychological domain (1 item).

The third factor was more difficult to interpret, but might represent a domain of 'social participation'. On this factor, the highest loading facets (>0.6) were information and leisure activities, both of which loaded on the environment domain on the original instrument.

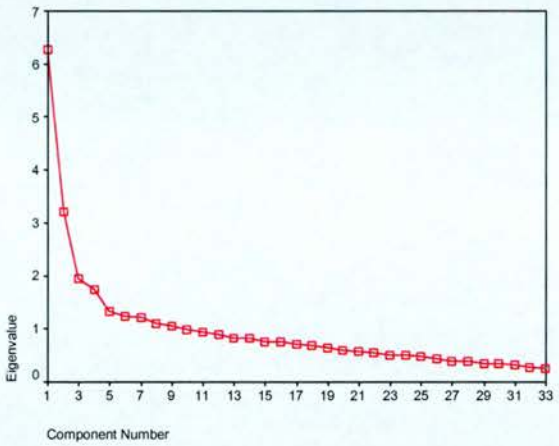
Finally, the fourth factor included facets related to physical and psychological well-being that might represent a 'physical and mental health' domain. On this factor, the highest loading facet (>0.6) was pain, with one other facet loading >0.5 (medication).

The structure of the five-factor solution was very similar (Table A9.26, Appendix 9). However, two facets from the social and emotional care/support domain (finance and physical environment), one item from the functional ability domain (mobility) and one item from the social participation domain (transport) formed an additional factor which appeared to reflect aspects of independence and integration which might represent an 'environment' domain (although differing from the original WHOQOL environment domain). In addition, one facet (special relationship) which loaded with a positive coefficient on factor 1 (social/emotional domain) and a negative coefficient on factor 4 (physical/mental health domain) at similar levels in both solutions, changed highest loading from factor 4 in the four-factor solution to factor1 in the five-factor solution.

All Items

For the complete set of 33 items (new items plus base items), the principal components analysis yielded nine factors with eigenvalues greater than one, explaining 57.7% of the variance. However, the seventh, eighth and ninth factors comprised two items only.

Figure 9.30: Exploratory Factor Analysis Scree Plot for All Items



As figure 9.30 shows, the scree plot of factors suggested that a five or six domain solution might provide the best fit for the current dataset, depending on interpretation of the scree drop test.

The five-factor solution explained 43.8% of the variance, compared with 47.5% for the six-factor solution.

The findings of the reliability analysis (section 9.3) suggested that new items formed two distinct components; and the correlation analysis (section 9.4) showed that these items had the highest correlations with their own domains, albeit that some significant cross correlations with other domains were noted. This pointed to the likelihood of a six-factor solution as the best fit for the current dataset (with the WHOQOL base items comprising 4 factors and the new items comprising 2 factors).

The results of the rotated six-factor solution (showing significant primary factor loadings >0.3 and secondary factor loadings ≥0.4) are presented in Table 9.26. The results of the five-factor solution are presented in Table A9.27 in Appendix 9 for comparison.

As shown in Table 9.26, the underlying structure of the complete set of 33 items in the WHOQOL-ID was consistent with that established for the base items only, but differed from the predicted 4 + 2 solution based on the original WHOQOL-BREF domains.

Table 9.26: Principal Components Analysis of All Items (6-factor solution)

Item	*Facet*	*Factor 1*	*Factor 2*	*Factor 3*	*Factor 4*	*Factor 5*	*Factor 6*
23	Home	0.74					
20	Personal relationships	0.65					
24	Health/social care	0.63					
22	Social support	0.58					
8	Safety	0.58					
5	Positive feelings	0.50		0.45			
21	Special relationship	0.45					
12	Finance	0.42					
29	Ridicule		0.85				
30	Discrimination		0.77				
27	Stigmatisation		0.74				
28	Victimisation		0.71				
35	Respect		0.47		0.43		
36	Acceptance		0.40		0.37		
17	ADL			0.71			
18	Work			0.65			
11	Body image			0.54			
19	Self esteem	0.48		0.52			
7	Thinking			0.50			
10	Energy			0.47			
6	Spirituality			0.39			
16	Sleep			0.32			
31	Enabling				0.77		
32	Empowerment				0.76		
33	Autonomy				0.67		
14	Leisure activities				0.44		0.41
13	Information				0.40		
3	Pain					0.61	
26	Negative feelings					0.56	
4	Medication					0.54	
25	Transport						0.61
15	Mobility						0.59
9	Physical environment						0.40

Data: All Clients - Combined Hospital and Community Groups ($N = 417$)

In the six-factor solution of all items, the first factor included a cluster of facets related to home, personal relationships, safety, social support and positive feelings, similar to that found for base items only, suggesting that a domain of

'social and emotional care and support' was robust across the two item sets. This first factor explained a similar proportion of the variance (19%) as for the base items only with all other factors accounting for less than 10%. Again, the highest loading facet on the first factor was home (>0.7), with two other facets loading >0.6 (personal relationships, health/social care) and three facets loading at >0.5 (social support, safety and positive feelings).

The second factor demonstrated the impact of the addition of six of the new items, which loaded on the 'social inclusion' factor in the analysis of new items only, and which maintained their integrity, loading as a separate item group in the analysis of all items. This finding was consistent with those reported in the correlations section (9.4) and suggested that these six items comprised a distinct factor reflecting a 'social inclusion' domain, tapping facets of quality of life not represented in the original WHOQOL instrument, but relevant to the lives of people with intellectual disabilities.

The third factor comprised a similar grouping of facets related to physical and psychological capacity as found in the analysis of base items only, suggesting that a domain of 'functional ability' might be robust across both item sets also.

The fourth factor comprised the other three new items (empowerment, enabling and autonomy) that loaded on the 'empowerment' factor in the analysis of new items, in this case loading together with two base items (leisure activities and information) to form an aggregate factor in the analysis of all items. This suggests that these three new items may have been tapping aspects of quality of life already included in the original WHOQOL structure, or that a different (and in the case of people with intellectual disabilities more coherent) item-factor structure was formed by the addition of these items. This aggregate factor might represent a domain of 'empowerment and participation'.

The fifth factor included the same three facets related to physical and psychological well-being as found in the analysis of base items only, which might reflect a 'physical and mental health' domain.

Finally, the sixth factor included three items (transport, mobility and physical environment) included in the possible 'environment domain' in relation to the five-factor solution of base items only.

The overall factor structure of the five-factor solution (Table A9.27, Appendix 9) was very similar to that found for the six-factor solution. A similar set of facets loaded at similar levels on the 'social and emotional care and support' factor (factor 1). The set of six 'social inclusion' facets remained as a separate factor, but moved in relative prominence to factor 3. The 'functional ability' and 'empowerment and participation' factors were maintained with similar facet groupings also (factor 2 and factor 4); and the 'physical and mental health' factor was identical (factor 5).

The major difference in the five-factor solution was that two of the 'environment' facets in factor 6 of the six-factor solution (transport and mobility) moved to the 'functional ability' factor (factor 2) and the third (physical environment) moved to the 'social and emotional care and support' factor (factor 1). In this respect, the five-factor solution provided a more parsimonious structure. This together with the affinity between new items and base items in the 'empowerment and participation' factor found in both the five- and six-factor solutions (which was not envisaged in the predicted 4 + 2 factor structure) suggested that the five-factor solution might be the superior structure, despite its slightly lower explanation of the variance.

Summary of Exploratory Factor Analysis

The factor solutions derived for the WHOQOL-ID suggested a different structure from that reported for the original instrument.

Table 9.27: Summary of Exploratory Factor Analysis Solutions by Item Set

Domains	New Items	Base Items		All Items	
	2 factor	4 factor	5 factor	5 factor	6 factor
Social and Emotional Care and Support		X	X	X	X
Functional Ability		X	X	X	X
Social Participation		X	X		
Physical and Mental Health		X	X	X	X
Empowerment and Participation				X	X
Empowerment	X				
Social Inclusion	X			X	X
Environment			X		X

As shown in Table 9.27 the core factors (social and emotional care/support; functional ability; physical and mental health; and social participation or empowerment/participation) were broadly consistent across the configurations of the base 24-item subset and the complete 33-item set. In addition, 6 new facets formed a distinct additional factor (social inclusion) within the set of all 33 items.

Although the pattern of these factor solutions may not have been predicted from the previous WHOQOL research, it is possible to account for the structures found for the adapted WHOQOL-ID in terms of the specific characteristics of people with intellectual disabilities, and the background of the particular clients in the present study.

All the ID clients in the present study were living in a 'cared-for' environment: 51% of the combined client group were in-patients of a learning disabilities hospital at the time of the study; and 49% lived in a range of staffed community

care houses, although all these individuals had formerly been hospital patients also.

In this context, the prominence of a 'care and support' factor is entirely coherent. The high loading facets on the domain of 'social and emotional care and support' form a strong and congruent thematic cluster in relation to ID clients, as much of their quality of life is dependent on where they live, their relationships with fellow residents and staff, the quality of health and social care received, and the extent to which they feel safe and supported, both emotionally and socially.

The dependency of the clients in the present study is relevant also. Only 17% of the combined client group were rated as having low dependency compared with 83% rated with medium or high levels of dependency. The domains of functional ability and social participation (base items) or empowerment and participation (all items) may be accounted for in relation to dependency within the 'cared-for' settings. Typically, dependency has influenced placement type and the likelihood of community resettlement (at least until total hospital closure plans were introduced). Even now, competencies and adaptive behaviours may be major determinants of where people live and what type of care they receive, with consequent effect on the quality of their lives.

Similarly, empowerment and social participation (particularly in relation to the availability of information and the provision of activities) may be influenced by the nature of the care regimen and care staff's perceptions of the aptitudes (or limitations) of clients in terms of their intellectual disabilities and any associated problems.

The effects of social isolation and *ex*clusion within institutional care have been well documented (Goffman, 1961; Emerson et al, 2000). In recent years, many service developments for people with intellectual disabilities have focussed on reducing inequalities and promoting social justice with the specific aim of enhancing quality of life. In this context, the 'social *in*clusion' domain is particularly relevant to ID clients whose lives may have been impoverished by segregation and discrimination.

These empirically derived domains reflect some of the key themes of the ideologically driven normalisation movement, for example as expressed in the so-called 'Five Service Accomplishments' (O'Brien, 1987). Within this framework, services achieving high quality standards (with implicit impact on the quality of life of residents) are described as those which provide *community presence* (being located in local neighbourhoods), support social *participation*, encourage skill development and *competence*, offer opportunities for meaningful *choice*, and foster *respect* between staff, service users and other members of the community.

Finally, in relation to the domain of 'physical and mental health', intellectual disability is associated with a higher rate of unrecognised illness (Howells, 1986;

Wilson and Haire, 1990; Fernando et al, 2001) and a higher prevalence of specific problems that may impact on quality of life compared with the general population. People with intellectual disabilities may be at greater risk of developing mental health problems as a result of the impact of life events in the context of reduced protective factors such as social support (Emerson et al, 2001). They are more likely to have a range of associated physical disabilities such as sensory impairment (Yeates, 1995; Kerr et al, 1996) or epilepsy (Bowley and Kerr, 2000); and many have physical health problems resulting from long standing health inequalities and lifestyle problems e.g. obesity linked with poor diet and lack of exercise (Robertson et al, 2000), or sexual health problems linked to lack of health education In addition, the typical lifespan of people with intellectual disabilities has increased over recent years (Hogg et al, 2000) however for some people, particularly those with Down's syndrome, the impact of dementia which occurs more often and with an earlier age of onset (Oliver and Holland, 1986; Holland, 2000) may adversely affect a quality of life already limited by other factors.

9.5.2 Confirmatory Factor Analysis

Confirmatory factor analysis was employed to test hypotheses about the underlying structure of the WHOQOL-ID.

Three initial hypotheses flowed from the earlier work on the original WHOQOL-BREF and from the conceptual model of the WHOQOL-ID:

H1 The WHOQOL-ID had a *similar factor structure* to that established for the WHOQOL-BREF, with the additional facets loading on existing domains (null hypothesis). In this model, the new items would not add significantly to the existing facets used to measure of quality of life.

H2 The WHOQOL-ID had a *similar core factor structure* to the WHOQOL-BREF, but with some of the additional facets loading on one or more new factors (first alternative hypothesis). In this model, the new items would add to the overall measure of quality of life.

H3 The WHOQOL-ID had a *different factor structure* to the original instrument (second alternative hypothesis).

The results of the reliability and correlation analysis of the current dataset provided no support for hypothesis 1, but suggested that the new items formed one or more separate domains as conceived by hypothesis 2. The results of the exploratory factor analysis failed to support hypothesis 1 also, but provided evidence for hypothesis 3, suggesting that the structure of the WHOQOL-ID might differ from that of the original instrument reflecting the specific characteristics of the people with intellectual disabilities.

Confirmatory factor analysis was carried out using EQS (Windows) Version 5.7b (Bentler and Wu, 1998) to test the two alternative models for the WHOQOL-ID as set out in H2 and H3 above. This was approached in the same three stages as the exploratory factor analysis, initially testing models for the subset of 9 new items only; then subset of 24 re-worded base items only; and finally the complete set of 33 items.

For reasons noted in the introduction to the factor analysis procedures (section 9.4), the combined client dataset ($N = 417$) from hospital and community settings was used for the confirmatory, as well as the exploratory, factor analysis. This dataset provided subject to variable and subject to estimated parameter ratios of 12:1 and 6:1 respectively, both of which were at the lower end of recommended limits (Nunnally, 1978; Hair etc al, 1998). As noted previously also, appropriate caution was exercised in relation to the potential for overestimation of fit in relation to models generated from the exploratory factor analysis.

New items

The original model envisaged in relation to the nine new items was a single domain structure (N.1). This model was compared with the subsequently developed conceptual model, which suggested a two-domain structure (N.2), which was supported by the exploratory factor analysis. Models N.1 and N.2 are presented in full in Tables A.9.28 and A.9.29 in Appendix 9. For model N.2, it was assumed that the two underlying factors were linked through a higher order factor representing elements of life experience related to 'social justice'.

Table 9.28: Summary of Fit Indices from Structural Equation Modelling of New Items

Fit Indices	Model N.1 1 Domain	Model N.2 2 Domain (EFA Model)
Chi Square (χ^2)	431.7, $df = 27$, $p < 0.001$	104.5, $df = 24$, $p < 0.001$
Comparative Fit Index (CFI)	0.652	0.931
Average Off-Diagonal Residuals	0.1114	0.0447

Data: All Clients - Combined Hospital and Community Groups ($N = 417$)

As shown in Table 9.28, the two-domain structure represented an improvement on the single domain structure on every fit index.

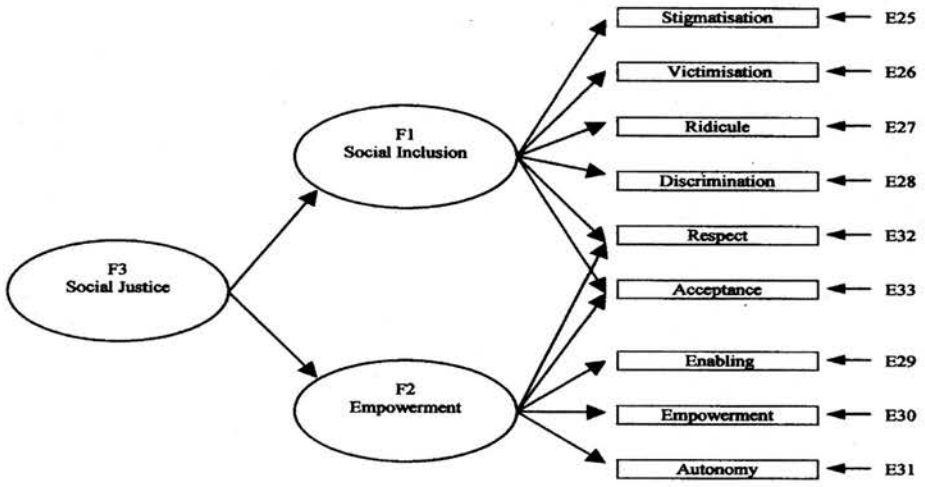
The large significant χ^2 values for both models suggested that neither model provided a good fit, since a statistically significant χ^2 denotes a model that fails to reproduce the observed data accurately (Bryant and Yarnold, 1998). However the chi square test is sensitive to sample size and for models with relatively few factors, the sample of 417 subjects would be considered quite small (Kline, 1994). In this case, the substantially smaller χ^2 value obtained for the two-domain

model (much closer to the critical value) suggested that this was the superior of the two models, even taking account of the potential for an overestimation of fit for model N.2 as it was derived from, and tested, on the same dataset.

The CFI was the preferred measure of fit used by the WHOQOL Group in the evaluation of the original scale, as it provides a better index of fit, taking into account both the degrees of freedom within the specified model and the sample size (WHOQOL Group, 1998). On this measure of fit (which ranges from 0 to1) a CFI of 0.9 indicates a good degree of fit for the model under consideration, and a CFI of 0.8 might be taken to represent an acceptable level of fit within the context of exploratory work with a relatively small sample size. In the current study, the single domain model CFI fell well below the acceptable fit level at <0.7, while the two-domain model CFI demonstrated a good level of fit at 0.93. (In view of this, no attempt to further refine the model was made, thus maximising parsimony).

The improvement of fit of the two-domain model was demonstrated also in the much lower figure for the average off-diagonal residuals. On this measure, the closer the residuals are to zero, the better the model fit, and a value of 0.05 or lower represents an acceptable fit.

Figure 9.31: Model N.2 (New items only)



The diagram for the superior two-domain model is shown in Figure 9.31. As shown the confirmatory factor analysis supported the two-factor structure for the nine new items with four facets loading on the social inclusion domain (stigmatisation, victimisation, discrimination and ridicule), three facets loading on the empowerment domain (enabling, empowerment and autonomy) and two facets loading on both domains (respect and acceptance). The hypothesised presence of a higher order factor was also confirmed.

Base items

The model established for the original WHOQOL-BREF was a four-factor structure with physical, psychological, social and environment domains (B.1). Initially, this model was compared with the alternative four-domain structure suggested by the exploratory factor analysis of the base items within the WHOQOL-ID (B.2). However, as the exploratory factor analysis had suggested that the three items from the original social domain tended to load together with items from the environment domain (on the hypothesised social and emotional care/support domain) a further comparison was made with a modified three-factor BREF structure with a composite social and environment domain (B3). Models B.1, B.2 and B.3 are presented in full in Tables A.9.30, A.9.31 and A.9.32 in Appendix 9. Following the original WHOQOL study, for all three models it was assumed that the primary factors were linked through a higher order factor representing quality of life.

For each competing model, the fit indices derived for the initial and final models (as modified by EQS programme recommendations) are presented in Table 9.29.

Table 9.29: Summary of Fit Indices from Structural Equation Modelling of Base Items

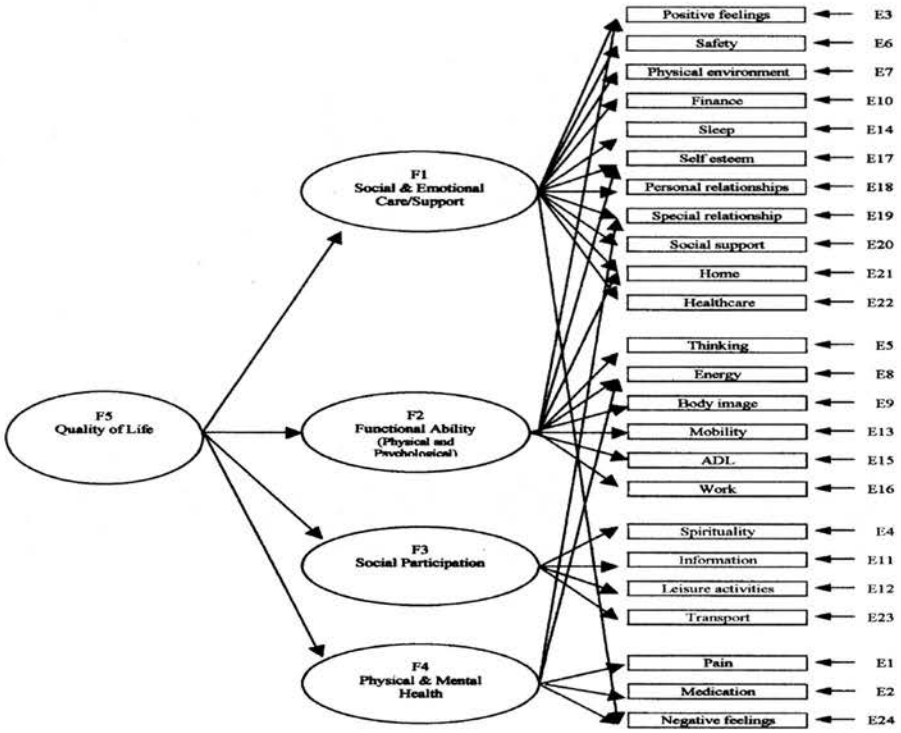
Fit Indices	Model B.1 4 Domain (BREF Model)	Model B.2 4 Domain (EFA Model)	Model B.3 3 Domain (Modified BREF)
	INITIAL MODELS		
χ^2	713.1, *df* = 248, p < 0.001	580.2, *df* = 245, p < 0.001	702.5, *df* = 250, p < 0.001
CFI	0.772	0.836	0.778
Ave. Off-Diag.	0.0546	0.0470	0.0546
	FINAL MODELS		
χ^2	628.5, *df* = 246, p < 0.001	514.0, *df* = 242, p < 0.001	635.5, *df* = 248, p < 0.001
CFI	0.812	0.867	0.810
Ave. Off-Diag.	0.0496	0.0412	0.0499

Data: All Clients - Combined Hospital and Community Groups (N = 417)

As shown in Table 9.29, the four-domain model B.2, based on the exploratory factor analysis structure, seemed to represent an improvement over the other models on every fit index, at both the initial and final model stages. Furthermore, the fit indices for the initial version of B.2 were superior to those of the final versions of the competing models. For all final models, the χ^2 value remained statistically significant, but for model B.2 this value was smaller and closer to the critical value. On the CFI, all final models demonstrated acceptable fit (>0.8) but model B2 approached a good level of fit at with a CFI of 0.87. Finally, model B.2 demonstrated the lowest average off-diagonal residuals.

The diagrams for the four-domain models B.2 and B.1 are shown in Figures 9.32 and 9.33 respectively.

Figure 9.32: Model B.2 (Base items only)

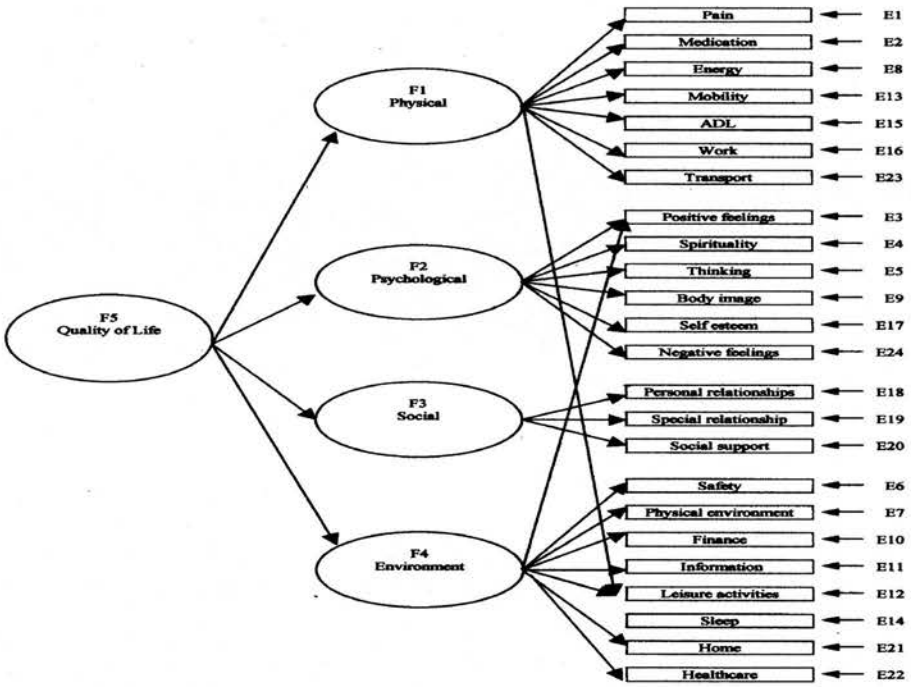


All three indices of fit suggested that the four-domain EFA based model B.2 was the superior of the models. However as the differences were relatively marginal, taking into account the size of the current data set compared with that of the original WHOQOL study (N>4000), and the fact this model was tested on the dataset from which it was derived, this finding must be approached with caution.

The confirmatory factor analysis supported the superior four-factor model B.2 for the 24 base items, with domains of social and emotional care/support, functional ability, social participation and physical/mental health as found in the exploratory factor analysis. The hypothesised presence of a higher order factor was also confirmed.

As shown in Figure 9.32, this solution was relatively parsimonious with no co-variation of facet errors and only six facets loading on two domains: positive feelings, self esteem and home loading on social and emotional care/support and on functional ability; special relationship loading on social and emotional care/support and on physical/mental health; energy loading on functional ability and on physical/mental health; and negative feelings loading on physical/mental health and on social and emotional care/support.

Figure 9.33: Model B.1 (Base items only)



As shown in Figure 9.33, the alternative four-factor BREF model B.1 for the base items, with physical, psychological, social and environment domains, also provides a relatively parsimonious solution with no co-variation of facet errors and only two facets loading on two domains (positive feelings loading on the psychological and environment domains, and leisure activities loading on the physical and environment domains). In addition, two facets did not load on the predicted BREF domain, but loaded on an alternative domain (transport loading on the physical rather than environment domain; and sleep loading on the environment rather than the physical domain). These unpredicted facet loadings and cross loadings, which were not found in the original WHOQOL study, seemed to be related to the characteristics of the client group. Also, in order to achieve the model B.1 solution, the social and environment factor disturbances were allowed to co-vary. This resultant structure echoed both the overall structure of the three-domain modified BREF model B.3 (with a similar level of fit) and factor 1 of the 4-domain EFA model B.2.

These findings tend to provide support for the more distinctive (EFA-based) client related solution of model B.2. However, with a larger dataset that would allow for the divided sample approach in relation to the exploratory and confirmatory analysis, and with relevant scale refinements as suggested by other aspects of the evaluation of psychometric properties, the four-domain BREF based model B.1 might still remain a viable model for this client group.

All items

As there was no established model for the WHOQOL-ID, the starting point for the confirmatory factor analysis was the factor solutions derived from the principal components analysis. This suggested either a five-domain model (A.1) or a six-domain model (A.2) for the complete set of items. In the absence of an appropriate WHOQOL-100 or WHOQOL-BREF comparator, these two models were compared with an aggregate model (A.3) of the solution obtained for the BREF model base items (B.1) plus the solution obtained for the new items (N.2).

Models A.1, A.2 and A.3 are presented in full in Tables A.9.33, A.9.34 and A.9.35 respectively in Appendix 9. Following the original WHOQOL study, for all three models it was assumed that the primary factors were linked through a higher order factor representing quality of life.

For the competing models A.1 and A.2, the fit indices derived for the initial and final models (as modified by EQS programme recommendations) are presented in Table 9.30. For the comparator model A.3, only one model is presented as this was derived from an aggregate of (already) final models.

Table 9.30: Summary of Fit Indices from Structural Equation Modelling of All Items

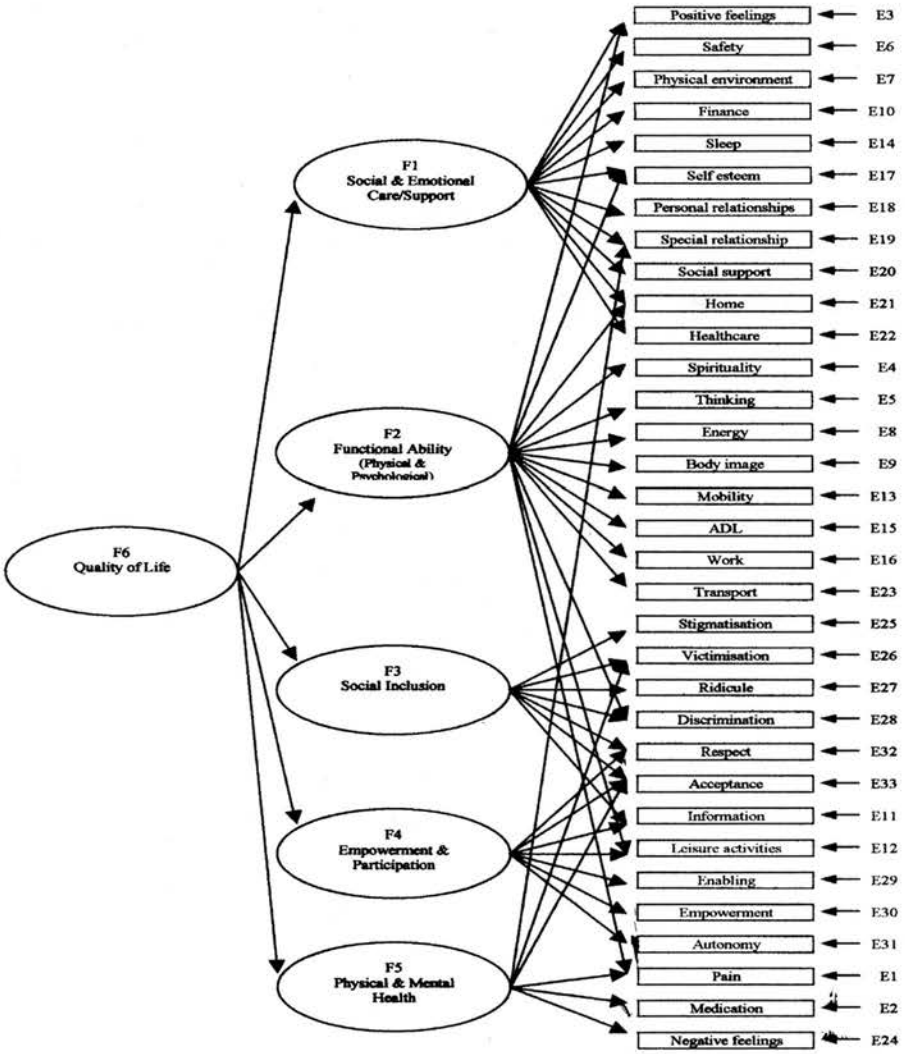
Fit Indices	Model A.1 5 Domain (EFA Model)	Model A.2 6 Domain (EFA Model)	Model A.3 6 Domain (B.1 + N.2)
	INITIAL MODELS		
χ^2	1219.5, *df* = 487, p < 0.001	1181.9, *df* = 484, p < 0.001	
CFI	0.792	0.802	
Ave. Off-Diag.	0.0555	0.0570	
	FINAL MODELS		*AGGREGATE MODEL*
χ^2	1031.2, *df* = 478, p < 0.001	1098.8, *df* = 481, p < 0.001	1220.6, *df* = 485, p < 0.001
CFI	0.843	0.825	0.791
Ave. Off-Diag.	0.0489	0.0525	0.0559

Data: All Clients - Combined Hospital and Community Groups ($N = 417$)

As shown in Table 9.30, the five-domain model A.1, based on the five-factor exploratory factor analysis structure, seemed to represent an improvement over the other models on every fit index, at both the initial (as appropriate) and final model stages. For all models, the χ^2 value remained statistically significant, but for model A.1 this value was smaller and closer to the critical value. On the CFI, both model A.1 and A.2 demonstrated acceptable fit (>0.8). However model A.1 approached a good level of fit at with a CFI of 0.84 and also demonstrated the lowest average off-diagonal residuals.

Although all three indices of fit suggested that the five-domain EFA based model A.1 was the superior of the three models, the differences in fit between this and the six-domain EFA model were relatively small. In contrast, the alternative six-domain model, based on the four-domain BREF-based model for the base items plus the two-domain model of the new items, demonstrated poor fit on all indices. This suggests that the new items cannot simply be 'added' to the basic scale, but rather, in conjunction with the re-worded BREF items, reflect a different psychometric pattern linked to the characteristics of ID clients. The diagrams for competing models A.1 and A.2 are shown in Figures 9.34 and 9.35 respectively.

Figure 9.34: Model A.1 (All items)



Once again, caution needs to be exercised in regard to the superiority of model A.1 in view of the client group size, the related single sample approach to the exploratory and confirmatory procedures (rather than a random spit-half design) and the possible impact of future scale refinements.

For the current dataset, the confirmatory factor analysis supported the superior five-factor model A.1 for all 33 items, with domains of social and emotional care/support, functional ability, social inclusion, empowerment/participation and physical/mental health as found in the exploratory factor analysis. The hypothesised presence of a higher order factor was also confirmed.

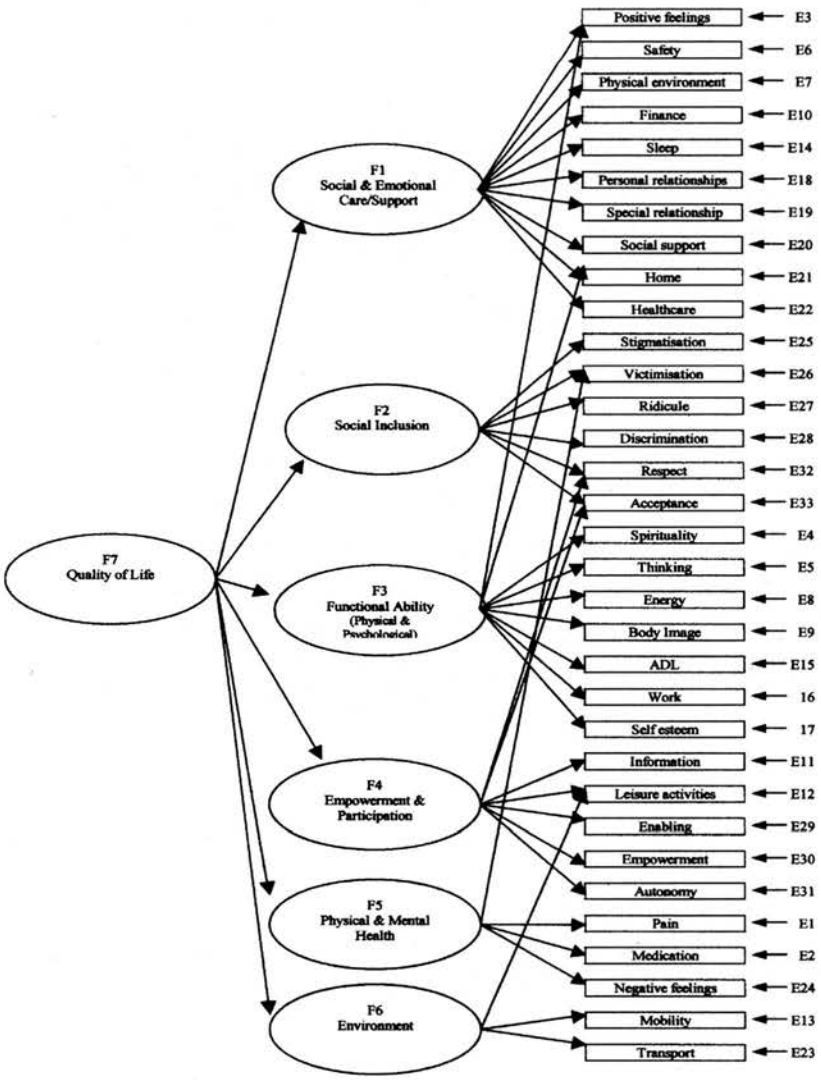
As shown in Figure 9.34, this solution was relatively parsimonious with no co-variation of facet errors. However, ten facets loaded on two domains: positive feelings, self esteem and home loading on social and emotional care/support and on functional ability; special relationship loading on social and emotional care/support and on physical/mental health; discrimination loading on social inclusion and functional ability; respect loading on social inclusion and empowerment/participation; victimisation loading on social inclusion and physical/mental health; information loading on empowerment/participation and social inclusion; leisure activities loading on empowerment/participation and functional ability; and pain loading on physical/mental health and functional ability. Also, one facet, acceptance, loaded on three domains: social inclusion, empowerment/participation and physical/mental health. All these cross loadings were congruent and were consistent with the characteristics of the client group.

Finally, model A.1 could be improved further by allowing the disturbances of the functional ability and social inclusion domains to co-vary. This revision of model A.1 produced a χ^2 value of 1008.5 ($df = 477$) with a CFI of 0.849 and an average off-diagonal residual value of 0.0439.

As shown in Figure 9.35, the six-factor model A.2 had five domains in common with the five-factor model A.1 (social and emotional care/support, social inclusion, functional ability, empowerment/participation and mental/physical health), but also had a sixth factor which reflected aspects of environment. In the exploratory factor analysis this sixth factor comprised primary loading facets of transport, mobility and physical environment, with leisure activities as a cross loading facet; however, in the confirmatory factor analysis, the physical environment facet loaded only on the social and emotional care/support domain, and the residual sixth factor included mobility, transport and leisure activities (which cross loaded from the empowerment domain).

Model A.2 was relatively parsimonious also, with no co-variation of facet errors. However, eight facets loaded on two domains positive feelings and home loading on social and emotional care/support and on functional ability; discrimination loading on social inclusion and functional ability; respect and acceptance loading on social inclusion and empowerment/participation; victimisation loading on social inclusion and physical/mental health; self esteem loading on functional ability and social and emotional care/support; and leisure activities loading on empowerment/participation and environment. These cross loadings were similar to those in found in model A.1, and were both congruent and consistent with the characteristics of the client group.

Figure 9.35: Model A.2 (All items)



Summary of Confirmatory Factor Analysis

The confirmatory factor analysis tended to support the exploratory factor solutions derived for the WHOQOL-ID, with the best fitting models for the complete set of 33 items (A.1) and for the subset of 24 base items (B.2) reflecting factors extracted in the principal components analysis. For these item sets, models derived from those established for the original WHOQOL instruments tended to show slightly poorer fit indices, although for the base items only (the most robust comparator) this finding was relatively marginal.

As shown in Table 9.31, the subset of new items produced a strong two-factor model (N.2) reflecting domains of social inclusion and empowerment. The subset of base items produced a moderately strong four-factor model (B.2) comprising domains of social and emotional care/support, functional ability, social participation and physical/mental health.

Table 9.31: Summary of Confirmatory Factor Analysis Solutions by Item Set

Domains	New Items Model N.2	Base Items Model B.2	All Items Model A.1
Social and Emotional Care and Support		X	X
Functional Ability		X	X
Social Participation		X	
Physical and Mental Health		X	X
Empowerment and Participation			X
Empowerment	X		
Social Inclusion	X		X
	CFI = 0.93	*CFI = 0.87*	*CFI = 0.85*

The set of all items produced a moderately strong five-factor model (A.1) with a configuration consistent with the separate models established for new and base items, comprising domains of social and emotional care/support, functional ability, physical/mental health, empowerment/participation and social inclusion.

The models for the subset of base items and the set of all items were not those predicted from the previous WHOQOL research, but were congruent in terms of facet-domain loadings and consistent with the specific characteristics of people with intellectual disabilities.

The impact of including six of the new facets in the adapted WHOQOL-ID was demonstrated most clearly in the robust domain of social inclusion, which remained separate and distinctive within both the new item (N.2) and all item (A.1) models. These new facets seemed to be measuring aspects of quality of life not included in the original WHOQOL scales, but suggested as having face validity by the focus groups and now established as having psychometric validity within the overall scale for clients with intellectual disabilities. The effect of the other three new facets was less distinctive, but just as relevant in terms of the client group, forming an empowerment domain in the new item model (N.2), which linked with base facets to produce an empowerment and participation domain within the all item model (A.1). These new facets may have been measuring some aspects of quality of life already tapped by base facets, but within the context of the complete set of item-facets, contributed to a model configuration that differed considerably from the core model of the original instrument.

Therefore, in relation to the current dataset, moderate support was found for the second alternative hypothesis (H3) that the WHOQOL-ID had a *different factor structure* to the original instrument. However, for both the base set of items and the complete set of items comprising the WHOQOL-ID, the comparative fit indices fell below the desirable level of 0.9, and the χ^2 values remained significant for both the best fitting model and the comparator BREF model.

Although the alternative WHOQOL-ID model emerged as superior in absolute terms, a much larger study, employing a split-half sample design for factor derivation and subsequent model testing, would be required before this could be established unequivocally.

Chapter 10

Individuals' Quality of Life - Analysis and Discussion of Results

The two quality of life measures completed by participants yielded a rich set of data about individuals' lifestyles, experiences and life quality. The Life Experiences Checklist (LEC) provided an objective measure of *general life experiences* in relation to the extent to which these samples of adults with intellectual disabilities and general public adults participated in the events and experiences common to the general population; and the WHOQOL-ID (or WHOQOL-BREF) provided a subjective measure of life quality in terms of individuals' overall *experience of life* within the framework of a wide range of quality of life facets.

10.1 Life Experiences

All 625 participants completed the standard version of the Life Experiences Checklist. As shown in Table 10.1, a total of 74 ID clients participated directly in the setting of an interview (13% of the hospital residents and 23% of the community clients); 343 proxy staff responded on behalf of ID clients (87% for hospital residents and 76% for community clients); and 208 members of the general public returned the self-completed measure by post.

Table 10.1: LEC Completion by Participant Group and Response Mode

Response Mode	Hospital (*N* = 213)		Community (*N* = 204)		Public (*N* = 208)	
	N	%	*N*	%	*N*	%
Direct Interview	28	13.1	46	22.5	-	-
Proxy Interview	185	86.9	158	77.5	-	-
Postal Self Completion	-	-	-	-	208	100.0

All participants completed every LEC item and hence there were no missing values in the subsequent data analysis. The fact that general public participants completed all items (without researcher assistance or support) suggested that items were perceived as straightforward and unambiguous; that responses could be identified easily[1]; and that there was minimal sensitivity about item content.

[1] Ten members of the public (4.8%) indicated that they had completed the assessment pack with help (mainly from a partner or relative, although three individuals mentioned more formal support from a carer, warden and nurse). The reason for, or extent of, such help was not specified.

Inter-Rater Reliability

In relation to the adults with intellectual disabilities, two researchers (the principal researcher and a research assistant) were involved in the interviews during which the Life Experiences Checklist was completed by the ID client directly or their proxy key worker. Therefore inter-rater reliability procedures were undertaken in connection with a subset of the first cohort to be assessed on this quality of life measure, which was the hospital group. The two raters completed LECs simultaneously in vivo on a total of thirty-four individuals, representing 13% of the 262 hospital residents available at the time the assessments commenced, or 16% of the final group of 213 hospital residents. In each case, the lead rater (an alternated role) interacted directly with the respondent (i.e. introducing the assessment and presenting the items) and both raters independently recorded responses, scored items and noted comments.

Ager et al (1997) reported very robust rates of inter-rater reliability for the LEC subscales (measured by proportion of agreements to total items) of 0.93 (home), 0.95 (freedom) and 0.97 (leisure, relationships and opportunities). For the purpose of comparison, the proportion of agreement formula was applied to the present inter-rater reliability sample of 34 individuals.

Table 10.2: LEC Inter-Rater Reliability

Inter-Rater Reliability (N = 34)		
LEC Scale	Proportion of Agreement	Correlation (Pearson's r)
Home	0.88	0.98
Leisure	0.91	0.98
Relationships	0.85	0.92
Freedom	0.91	0.98
Opportunities	0.82	0.97
Total Scale	0.87	0.99

On this basis, the present sample produced satisfactory (albeit slightly lower) rates of inter-rater reliability, ranging from 0.82 (opportunities) to 0.91 (leisure, freedom). However, as shown in Table 10.2, slightly higher rates of inter-rater reliability overall were found on a correlational basis, with subscale reliability ranging from $r = 0.92$ (relationships) to $r = 0.98$ (home, leisure, freedom).

In relation to the general public group, no inter-rater reliability procedures were applicable for the self-completed response format.

Participant Groups and General Population Sample Comparisons

The LEC Manual (Ager, 1998) provides data from a general population sample that may be used as a reference group in order to compare response patterns in relation to item, subsection and total scores. This sample comprised 410 'householders' living in a combination of urban, suburban and rural settings in and around Leicester, who completed the LEC by self-rating (Ager et al, 1988). As this reference group sample was similar to the general public group in the current study, the comparison was of particular interest.

The series of tables below show the percentage of the reference sample (R in blue) reporting that a LEC item applied to them; and the percentage of the hospital group (H), community group (C) and general public group (P in violet, for ease of comparison) in the current study responding similarly positively to each item. Thereafter, summary statistics for the LEC item, subsection and total scores are presented.

Home

For the participant groups and the general public reference group, the percentage of individuals responding positively to items in the home subsection is presented in Table 10.3.

Table 10.3: Participant and Reference Group Comparison – LEC Home Subsection

	LEC Items – Home	H	C	P	R
		% Positive Response			
1	My home has more rooms (counting living-rooms and bedrooms) than people	16	100	91	79
2	My home is well decorated (e.g. it does not require a lot of repapering, painting etc.)	98	100	91	73
3	My home is carpeted and has comfortable furniture	97	100	99	91
4	My home has a garden	55	94	89	90
5	I have never been attacked by someone when at home	55	57	86	82
6	I have never had anything of mine stolen from home	77	89	70	68
7	I use a telephone at home at least once a week	7	16	97	79
8	My home has central heating	100	100	96	75
9	Visitors have sometimes said how nice they think my home is	55	99	92	75
10	I have my own room (or share with my partner only)	39	99	97	88

H: Hospital group C: Community group P: Public group R: Reference general population sample

(i) General public adults:

The response profile of the two general public groups was similar on some items e.g. similar proportions of people reported that their homes were carpeted and had comfortable furniture (item 3), and had a garden (item 4); and similar proportions of individuals reported not having been attacked in their home (item 5), and not having had things stolen from their homes (item 6).

However there were differences on other items, which may have reflected differences associated with the two settings in England and Scotland, but were more likely to have related to the impact of social change over the past decade or so (there were thirteen years between the two sets of data collection). For example, the data suggested that a higher proportion of the later (2001) Scottish sample of the general public had a home telephone which they used at least once per week (item 7); had centrally heated homes (item 8) which were well decorated (item 2); and had visitors who made complimentary remarks about their home (item 9).

(ii) Adults with intellectual disabilities:

The profile of the community group was similar to that of the general public group on the majority of items, indicating that the general home circumstances of the adults with intellectual disabilities in the community were similar to that of the general population.

The profile of the hospital group was more varied. There was a level of positive response similar to that of the other groups on some items e.g. similar proportions of respondents reporting that homes (wards) were well decorated (item 2); were carpeted and had comfortable furniture (item 3); and were centrally heated (item 8). However, compared with other groups, fewer hospital residents (55%) lived in wards with outside space that could be construed as their own garden (item 4); fewer residents (39% only) had their own bedroom (item 10); and fewer residents (55%) had experienced visitors making positive remarks about their 'home' (item 9). Finally, the institutionalised nature of 'group living' in hospital was reflected clearly in the reports that only 16% of hospital residents lived in a home with more rooms than people (item 1), compared with 100% of community clients, 91% of the current general public group and 79% of the reference group sample.

Only a small proportion of the adults with intellectual disabilities in either group (7% of hospital residents and 16% of community clients, compared with 97% of the general public participants and 79% of the general public reference group) reported regular use of the home telephone (item 7), but this seemed to be a function of the level of dependency of the ID adults rather than absence of the facility or procedural prohibition on its use.

However, of greater concern was that only 55% of hospital residents and 57% of community clients had *not* been attacked by someone in their home (item 5) compared with over 80% of the two general public samples, suggesting that approximately half the adults with intellectual disabilities had been subject to such an attack within the confines of a living place that most had not chosen, or participated in choosing, for themselves (see freedom section) and the majority had limited capacity to change.

(iii) Study participants:

For each group of participants in the current study, the proportion of positive and negative responses to items in the home subsection was further analysed in a series of 3*2 chi-square tests. The summary statistics from these analyses are presented in Table 10.4.

Table 10.4: Analysis of LEC Home Items for Participant Groups

Item	Home Facet	χ^2	*df*	*P* <
1	Sufficient rooms	412.735	2	0.001
2	Well decorated	23.378	2	0.001
3	Comfy furnishings	LEF	-	-
4	Garden	108.588	2	0.001
5	Never been attacked	53.892	2	0.001
6	Never had things stolen	22.364	2	0.001
7	Use of telephone	423.188	2	0.001
8	Central heating	LEF	-	-
9	Positive visitor remarks	156.627	2	0.001
10	Own room	281.513	2	0.001

LEF: Low expected frequencies – χ^2 statistics unreliable

Significant differences were found between the hospital residents, community clients and general public in relation to eight[2] out of the 10 items, with χ^2 values ranging from 22.364 to 423.188 (all significant at $p < 0.001$), confirming the pattern of between group differences in relation to the features and environment of their homes/wards.

Leisure

For the participant groups and the general public reference group, the percentage of individuals responding positively to items in the leisure subsection is presented in Table 10.5.

(i) General public adults:

The two general public groups showed broadly similar response profiles in relation to visiting friends/relatives for a meal at least once a month (item 11); attending a local club, class or meeting once per month (item 14); meeting friends/relatives at least once a week (item 16); going to church (item 18); having a hobby or interest (item 19); and having lots [of activities] to do at home (item 20).

[2] On the remaining two items, some cells were found to have low expected frequencies (50% of cells with expected counts < 5 on items 3 and 8) and the resulting chi-square statistic was likely to be an overestimate and therefore unreliable. However, on both items all three groups responded positively at 96% or above and hence further analysis was not required.

Table 10.5: Participant and Reference Group Comparison – LEC Leisure Subsection

	LEC Items – Leisure	H	C	P	R
		% Positive Response			
11	I visit friends or relatives for a meal at least once a month	18	30	60	52
12	I go to a café or restaurant for a meal at least once a month	44	87	71	34
13	I do some sport at least once a month	7	25	49	35
14	I go to a local club, class or meeting at least once a month	6	39	47	35
15	I go to the cinema or theatre at least once a month	1	15	26	12
16	I go out to meet friends or relatives (e.g. at the pub or in someone's home) at least once a week	12	23	64	70
17	I go away on holiday for at least two weeks each year	1	24	75	46
18	I go to church (or other place of worship) at least once a month	10	16	22	23
19	I have a hobby or interest (e.g. photography or collecting)	7	24	72	63
20	There is lots for me to do at home (e.g. play records, watch videos, play games, read books etc.)	94	94	99	89

H: Hospital group C: Community group P: Public group R: Reference general population sample

However twice as many of the current general public group (71% compared with the 34% of the reference sample) had a meal in a café or restaurant at least once per month (item 12); more individuals (49% compared with the 35% of the reference sample) played sport at least once per month (item 13); twice as many people (26% compared with the 12% of the reference sample) went to the theatre at least once per month (item 15); and a higher proportion of the group (75% compared with 46% of the reference sample) had a holiday of at least two weeks each year (item 17). These differences may be artefacts of the particular general public samples drawn in each case (apart from location, the demographics of the reference group are not described in the LEC Manual). However, some of these differences may be accounted for in terms of the increasing affluence of the population over the 13 years (meals out, holidays, cinema and theatre going); and increasing publicity about the importance of healthy lifestyles in recent years may account for the differential rates of engagement with sporting activity.

(ii) Adults with intellectual disabilities:

The profile of both groups of adults with intellectual disabilities was similar to the public on one item only, with 94% of hospital residents and community clients reporting having lots [of activities] to do at home (item 20).

On many leisure items, fewer adults with intellectual disabilities reported activity than the public group and reference group samples; and fewer hospital residents reported engagement to criterion level compared with community clients. For example, only 18% of hospital residents and 30% of community clients visited friends/relatives for a meal at least once per month (item 11) compared with over 50% in both public samples; only 12% of hospital residents and 23% of community clients went out to meet friends/relatives at least once per week (item 16) compared with over 60% in both public groups; only 1% of the hospital group and 24% of the community group had a holiday of at least two weeks each

year (item 17) compared with 75% of the contemporaneous public group and 46% of the earlier reference group; and only 7% of the hospital group and 24% of the community group had a hobby or interest (item 19) compared with over 60% of both the public group samples.

On some leisure items, the community group reported similar proportions of positive involvement as one or other of the general public groups; however, these tended to be leisure activities in which fewer members of the relevant public group reported engagement. For example, 25% of community clients were 'doing some sport' at least once a month (item 13) compared with 35% of the public reference group sample (and 49% of the public group); 39% of community clients attended a local club, class or meeting at least once a month (item 14) compared with 35% of the reference group (and 47% of the public group); and 15% of the community group went to the cinema or theatre at least once a month (item 15) compared with 12% of the reference group (and 26% of the public group). However on all these items, smaller proportions of hospital residents than all other groups reported taking part (only 7% did some sport, 6% attended a local club or class and 1% went to the cinema or theatre).

The only item on which the level of reported activity for both the hospital and community groups was not dissimilar to the public groups was attending church at least once a month (item 18), with 10% of hospital residents and 16% of community clients reporting positively on this item, compared with 22% of the public group and 23% of the reference group sample. However, this was the leisure item for which scores were the lowest across all groups.

Finally, on one item, going to a café or restaurant for a meal at least once per month (item 12), the level of reported activity of the community group at 87% exceeded that of all other groups, including the current study public group. At one level, this seemed to be a somewhat anomalous finding, as regular meals out requires, usually, an appropriate level of disposable income, the capacity to get to the location (requiring personal mobility and/or use of transport) and an available social network (friends, family). However, there was some anecdotal evidence that for the community group this was not so much a personally selected social activity, but more of a staff organised occupational activity scheduled as part of clients 'day programmes' using local community facilities (e.g. cafés, community centres etc.).

Within the current study, the community and public groups lived within the same range of locations and therefore could be assumed to have access to the same range of local leisure facilities. However, a similar level of activity on the leisure items (within approximately 10%) was reported on three items only (14: local club/class; 16: church; and 10: home activities). In contrast, the level of activity within the general public group was at least twice that of the community group on five items (11: visit friends/relatives for meal; 13: sport; 16: go out to meet friends/relatives; 17: holidays; and 19: hobby). This suggested that despite the aspirations for supported living in the community, for many community clients

the move had not produced a similar range of life experiences as their non-disabled neighbours, nor a lifestyle approaching that of the public in relation to this set of leisure activities.

(iii) Study participants:

For each group of participants in the current study, the proportion of positive and negative responses to items in the leisure subsection was further analysed in a series of 3*2 chi-square tests. The summary statistics from these analyses are presented in Table 10.6.

Table 10.6: Analysis of LEC Leisure Items for Participant Groups

Item	Leisure Facet	χ^2	*df*	*P* <
11	Meal with friends / relatives	83.775	2	0.001
12	Meal in café / restaurant	87.528	2	0.001
13	Play sport	97.378	2	0.001
14	Attend club / class	95.426	2	0.001
15	Go to cinema / theatre	56.681	2	0.001
16	Meet friends / relatives	143.211	2	0.001
17	Holidays	256.266	2	0.001
18	Church	11.037	2	0.01
19	Hobby / interest	216.277	2	0.001
20	Home activities	6.734	2	0.05

Significant differences were found between the hospital residents, community clients and general public in relation to all ten items, with χ^2 values ranging from 6.734 to 256.266 (with corresponding levels of significance between $p < 0.05$ and $p < 0.001$), confirming the pattern of between group differences in relation to social and leisure activities.

Relationships

For the participant groups and the general public reference group, the percentage of individuals responding positively to items in the relationships subsection is presented in Table 10.7.

(i) General public adults:

The response profile of the two general public groups was broadly similar on nine out of the ten relationship items: similar proportions of people reported that they had several close friends (item 21); felt loved and accepted by those they lived with (item 22); were addressed in a formal manner to a similar extent (item 24); were married or had a steady partner (item 25); had friends to stay once a year (item 26); had access to supportive people in times of sadness (item 27);

lived in mixed gender homes (item 28); stayed overnight with friends once a year (item 20); and got on well with their family (item 30).

Table 10.7: Participant and Reference Group Comparison – LEC Relationships Subsection

	LEC Items – Relationships	H	C	P	R
		% Positive Response			
21	I have several close friends	11	30	86	78
22	I feel loved and accepted by those who live with me	82	92	88	79
23	I am called by my first name by those who live with me	100	100	81	68
24	Some people address me formally (that is call me Mr, Mrs, or Ms ----------)	96	97	53	50
25	I am married (or have a steady partner)	1	2	80	70
26	I have friends to stay with me at home at least once a year	0	1	63	51
27	When I am sad there are people who listen to me and help me	64	88	86	76
28	There are both men and women living in my home	65	56	56	55
29	I stay overnight with friends at least once per year	1	3	58	47
30	I get on well with my family	63	68	94	88

H: Hospital group C: Community group P: Public group R: Reference general population sample

There was an interesting (although small) difference on item 23: 81% of the current general public group, compared with only 68% of the general public reference sample, reported that they were called by their first name by those who lived with them. This seemed to suggest that households in the Scottish sample may have contained more adults (e.g. extended as well as nuclear family members), or that some children in these households may have called parents by first names. However, the difference noted on this item may have reflected respondent misunderstandings or completion errors.

(ii) Adults with intellectual disabilities:

On some relationship items, the picture for adults with intellectual disabilities was at the response extremes: everyone in the hospital and community groups was called by their first name by those with whom they lived (item 23); but almost none of the hospital residents or community clients was married or had a partner (item 25), had friends to stay (item 26), or stayed overnight with friends (item 29). However, similar proportions of adults with intellectual disabilities as general public felt loved and accepted by those who lived with them (item 22); similar numbers of hospital residents and community clients had both men and women living in their homes (item 28) although these tended not be spouses; and similar proportions of community clients as general public had access to supportive people in times of sadness (item 27).

On other items, the relative impoverishment of the relationships of the adults with intellectual disabilities, especially the hospital residents, was reflected. For example, only 30% of the community group and 11% of the hospital group were reported to have 'several close friends' (item 21) compared with 86% of the general public group and 78% of the reference group; and only 68% of the

community group and 63% of the hospital group were reported to get on well with their families compared with 94% of the public group and 88% of the reference group (item 30).

Finally, there was one anomalous item. Almost twice as many adults with intellectual disabilities (96% of the hospital group and 97% of the community group) as members of the public (53% of the public group and 50% of the reference group) reported that some people addressed them formally (item 24). It is difficult to account for this. The ID clients, like other members of the general population would be expected to receive their share of formal communications: both written communications, for example from government departments (benefits office), the NHS (GP surgery or hospital appointment) and unsolicited mail shots (to those on the electoral register); and verbal communications, for example on being introduced to someone in a formal setting. However, it is hard to see how this alone could account for twice as many ID adults as general public reporting being addressed formally by some people. The most likely explanation may be found in the combination of the high proportion (82% overall) of proxy staff responding on behalf of the ID adults and the connotation of ideological 'value' implicit in positive responses on this item.

(iii) Study participants:

For each group of participants in the current study, the proportion of positive and negative responses to items in the relationships subsection was further analysed in a series of 3*2 chi-square tests. The summary statistics from these analyses are presented in Table 10.8.

Table 10.8: Analysis of LEC Relationships Items for Participant Groups

Item	Relationships Facet	χ^2	*df*	*P* <
21	Several close friends	261.730	2	0.001
22	Feel loved and accepted	9.439	2	0.01
23	Called by first name	85.676	2	0.001
24	Addressed formally	177.565	2	0.001
25	Married or partner	431.604	2	0.001
26	Have friends to stay	324.730	2	0.001
27	Support when sad	43.875	2	0.001
28	Mixed sex home	4.916	2	NS
29	Stay overnight with friends	260.849	2	0.001
30	Get on well with family	60.024	2	0.001

Significant differences were found between the hospital residents, community clients and general public in relation to nine[3] out of ten items, with χ^2 values ranging from 9.439 to 431.604 (with corresponding levels of significance

[3] On one remaining item (28, mixed sex homes) no significant difference was found between the groups. All three groups responded positively at between 56-65%

between $p < 0.01$ and $p < 0.001$), confirming the pattern of between group differences in social relationships.

Freedom

For the participant groups and the general public reference group, the percentage of individuals responding positively to items in the freedom subsection is presented in Table 10.9.

Table 10.9: Participant and Reference Group Comparison – LEC Freedom Subsection

	LEC Items – Freedom	H	C	P	R
		% Positive Response			
31	I can spend time by myself (in privacy) when I want to	39	90	95	86
32	I chose (or helped to choose) how my home is decorated	9	57	95	84
33	I myself chose to live in my present house	1	2	76	76
34	I have a bank or post office account from which I can withdraw money	2	95	97	78
35	Meal times are changed to fit in with my plans	3	6	84	66
36	I choose for myself what I do in my spare time	66	81	94	89
37	I have a vote in elections	1	77	98	92
38	I have my own personal possessions (which others may use if I choose)	99	100	97	85
39	I earn some money (other than benefit or pension)	5	3	68	56
40	I choose my own clothes	38	64	97	95

H: Hospital group C: Community group P: Public group R: Reference general population sample

(i) General public adults:

The response profile of the two general public groups was broadly similar on eight out of the ten freedom items: similar proportions of people reported that they could spend time alone when they wished (item 31); had chosen how their home was decorated (item 32); had chosen to live in their present house (item 33); could choose what to do in their spare time (item 36); had a vote in elections (item 37); had their own personal possessions (item 38); earned some money, other than benefits or pension (item 39); and chose their own clothes (item 40).

However, a higher proportion of the current public group (97%) had a bank or post office account (item 34) compared with the reference public group (78%); and meal times were more often changed to fit into respondents' plans (item 35) for the current public group (84%) than the reference group (66%). The differential general public responses on these two items may have reflected further aspects of social change over time, or may have been linked to the specific characteristics of the two samples. For example, in the late 1980s, when data for the reference group sample were collected, unemployment was higher than in 2001, particularly in areas affected by major industrial change and workforce reduction, and this may have affected the numbers of people with bank accounts; on the other hand, the precise demographics of the reference group was unknown, but approximately 60% of the current public group were

male, 31% of the group had received tertiary education and 63% were in paid employment, any combination of which could have accounted for the higher proportion of bank accounts in this group.

(ii) Adults with intellectual disabilities:

The profile of the community group was broadly similar to one or both general public groups on four items, with similar proportions of community clients reporting that they could spend time alone when they wished (item 31); had a bank or post office account (item 34); could choose what to do in their spare time (item 36); and had their own personal possessions (item 38).

Only 57% of community clients had helped to chose how their home was decorated (item 32) compared with 95% of the current public group and 84% of the reference group sample; 77% had a vote in elections (item 37) compared with 98% of the current public group and 92% of the reference group sample; and only 64% chose their own clothes (item 40) compared with 97% of the current public group and 95% of the reference group sample. The differences on these items may have been related to the levels of dependency of this group of community clients; although in the light of this and the fact that only 22.5% of these clients were able to contribute to the assessment directly, it should be noted that the figure of 77% having a vote in elections reflects the coding guidance provided in the LEC Manual, which emphasises electoral registration and hence potential to vote, rather than active and informed voting.

On many items, the relative lack of freedom of the hospital group, and the impact of institutionalisation on these individuals was reflected. For example, only half as many hospital residents (39%) as community clients or general public (on average 90%) reported being able to spend time alone in private (item 31); only 9% of the hospital group had chosen (or helped choose) how their home/ward was decorated (item 32) compared with 57% of the community group, 95% of the public group and 84% of the reference group; only 66% were reported to choose what to do in their spare time (item 36) compared with 81% of community clients and approximately 90% of the public; and only just over half as many hospital residents (38%) as community clients (64%) were reported to choose their own clothes (item 40) despite the similar levels of dependency of these two groups. However, for two items, the picture painted for the hospital group, although impoverished compared to their community counterparts, may have reflected a more accurate picture of their circumstances: only 2% of hospital residents were reported to have a bank or post office account (item 34) compared with 57% of community clients (again reflecting coding guidance that centrally managed hospital accounts do not meet the required criterion); and only 1% were reported to have a vote in elections (item 37).

Finally, on three items the lack of freedom of *both* groups of adults with intellectual disabilities was apparent: only 1% of hospital residents and 2% of community clients had chosen to live in their present residence (item 33); only

3% of hospital residents and 6% of community clients experienced mealtime flexibility (item 35); and only 5% of hospital residents and 3% of community clients earned any money apart from benefits or pension (item 39).

(iii) Study participants:

For each group of participants in the current study, the proportion of positive and negative responses to items in the freedom subsection was further analysed in a series of 3*2 chi-square tests. The summary statistics from these analyses are presented in Table 10.10.

Table 10.10: Analysis of LEC Freedom Items for Participant Groups

Item	Freedom Facet	χ^2	*df*	*P* <
31	Spend time in privacy	217.191	2	0.001
32	Chose décor	316.655	2	0.001
33	Chose present home	402.485	2	0.001
34	Bank or post office account	537.070	2	0.001
35	Flexible mealtimes	407.113	2	0.001
36	Choose spare time activities	52.381	2	0.001
37	Vote in elections	452.662	2	0.001
38	Personal possessions	LEF	-	-
39	Earn money	302.150	2	0.001
40	Choose own clothes	164.665	2	0.001

LEF: Low expected frequencies – χ^2 statistics unreliable

Significant differences were found between the hospital residents, community clients and general public in relation to nine[4] out of ten items, with χ^2 values ranging from 52.381 to 452.662 (all significant at $p < 0.001$), confirming the pattern of between group differences in relation to the extent and type of freedom afforded by their circumstances and lifestyles.

Opportunities

For the participant groups and the general public reference group, the percentage of individuals responding positively to items in the opportunities subsection is presented in Table 10.11.

(i) General public adults:

The response profile of the two general public groups was broadly similar on all items in the opportunities section. Over 90% of the public reported that local shops were a short walk away from where they lived (item 41); that they

[4] On the remaining item, some cells were found to have low expected frequencies (50% of cells with expected counts < 5 on item 38) and the resulting chi-square statistic was likely to be an overestimate and therefore unreliable. However, all three groups responded positively at 97% or above on this item and hence further analysis was not required.

travelled by car or public transport at least once a week (item 42); that they could make drinks or snacks whenever they wished (item 45); that they carried out some domestic tasks in the home (item 46); and that they enjoyed what they did during the day (item 48). Over 70% of both public groups reported being able to see their doctor easily if they were unwell (item 43); participated in cooking meals at least once a week (item 44); and regarded what they did during the day as of value to others (item 49). Finally, just over 40% of the public had a pet (item 47); and 32% of the current public group and 23% of the reference group were being taught a new skill (item 50).

Table 10.11: Participant and Reference Group Comparison – LEC Opportunities Subsection

	LEC Items – Opportunities	H	C	P	R
		% Positive Response			
41	Local shops are a short walk away	1	83	92	92
42	I travel by car or public transport at least once a week	29	91	96	91
43	When I am sick I can get to see a doctor easily (doctor visits or is just walking distance away)	100	100	85	81
44	I cook meals (perhaps with help) at least once a week	12	26	85	78
45	I can make myself drinks or snacks whenever I want to	23	73	99	94
46	I do some jobs in the home (e.g. washing up, cleaning)	31	41	99	94
47	I have a pet	1	9	41	46
48	I enjoy what I do during the day	76	97	90	83
49	What I do during the day is of help or value to others	24	24	76	70
50	I am being taught some new skill	13	39	32	23

H: Hospital group C: Community group P: Public group R: Reference general population sample

(ii) Adults with intellectual disabilities:

The response profile of the community group was similar to that of the public on four items: similar proportions of community clients reported that shops were a short walk away from where they lived (item 41); that they travelled by car or public transport at least once a week (item 42); that they enjoyed what they did during the day (item 48); and that they were being taught a new skill (item 50). However, only 26% of the community clients cooked, or helped cook, a meal once a week (item 44) compared with 85% of the public group and 78% of the reference group; only 73% reported being able to make drinks or snacks whenever they wished (item 45) and only 41% participated in domestic tasks (item 46) compared with 99% of the public group and 94% of the reference group in each case; only 9% had a pet (item 47); and only 24% considered what they did during the day as of value to others (item 49).

For the hospital group, the response profile demonstrated that considerably fewer of these hospital residents were afforded the range of opportunities enjoyed by other members of society. The hospital campus was situated slightly more than

the 15-20 minute criterion from local shops[5] (item 41) so many residents had limited or infrequent access to shops, and only one resident (1% rounded value) had a pet (item 47). Only one third of hospital residents compared to community clients travelled by car or public transport once a week (item 42), could make drinks or snacks when they wished (item 45) or were being taught a new skill (item 50); and only half as many hospital residents as community clients participated in cooking a meal once a week (item 44).

Nevertheless, 76% of the hospital group were reported to enjoy what they did during the day (item 48), which was similar to the level of the reference group (83%) though less that the comparator community group (97%) or current public group (90%). In addition, similar proportions of both hospital residents and community clients participated in domestic tasks (item 46); were reported to consider that what they did during the day was of value to others (item 49); and finally everyone in both groups had easy access to a doctor if they were unwell (item 43), which represented a higher proportion than found in the public groups.

(iii) Study participants:

For each group of participants in the current study, the proportion of positive and negative responses to items in the opportunities subsection was further analysed in a series of 3*2 chi-square tests. The summary statistics from these analyses are presented in Table 10.12.

Table 10.12: Analysis of LEC Opportunities Items for Participant Groups

Item	Facet	χ^2	*df*	*P* <
41	Local shops close	437.111	2	0.001
42	Travel by car / public transport	290.061	2	0.001
43	Easy access to doctor	59.935	2	0.001
44	Cook / help cook meals	258.670	2	0.001
45	Make drink / snack	277.316	2	0.001
46	Do some domestic tasks	228.924	2	0.001
47	Have pet	135.001	2	0.001
48	Enjoy daytime activities	43.704	2	0.001
49	Daytime activities of value	150.443	2	0.001
50	Learning new skill	37.872	2	0.001

Significant differences were found between the hospital residents, community clients and general public in relation to all ten items, with χ^2 values ranging from 43.704 to 437.111 (all significant at $p < 0.001$), confirming the pattern of between group differences in relation to the range of opportunities presented or experienced.

[5] One proxy staff considered the shops could be reached in 15-20 minutes, but must have been a fast walker, as all other proxy staff and hospital residents responded negatively to this item.

LEC Subsection and Total Scores

The mean and standard deviation of total and subsection scores for each of the current study groups and the general population reference sample are presented in Table 10.13.

Table 10.13: Mean Subsection and Total Scores for Participant Groups and General Population Reference Group

Group	*N*	Home	Leisure	Relationships	Freedom	Opportunities	LEC Total
Hospital	213	6.0 (± 1.5)	2.0 (± 1.2)	4.8 (± 1.1)	2.6 (± 1.3)	3.1 (± 1.8)	18.5 (± 4.7)
Community	204	8.5 (± 0.8)	3.8 (± 1.7)	5.4 (± 1.1)	5.8 (± 1.5)	5.8 (± 1.6)	29.2 (± 4.4)
General Public	208	9.1 (± 1.2)	5.6 (± 2.0)	7.4 (± 2.0)	9.0 (± 1.2)	7.9 (± 1.3)	39.3 (± 5.1)
Reference	410	8.0 (± 1.9)	4.6 (± 2.0)	6.6 (± 2.2)	8.0 (± 1.8)	7.5 (± 1.6)	34.8 (± 6.6)

Table 10.13 shows the differences between the current public group and the reference group; and it is apparent that the community group scores approached that of the general public more closely than those of the hospital group.

For the reference sample of general public adults, the LEC Manual supplies the centile distribution of subsection and total scores, providing a framework for comparison of domain scores both within and between groups. For ease of reference, the centile distribution of subsection scores is reproduced in Table 10.14 with the approximated 'average' score profile for the general population superimposed in red.

Table 10.14: Centile Distribution of LEC Subsection Scores for General Population Reference Sample (*N*=410)

Subsection Score	Home	Leisure	Relationships	Freedom	Opportunities
0					
1	1	1	1		
2	1	6	2	1	1
3	1	15	5	1	1
4	3	30	10	3	2
5	6	48	17	6	5
6	11	68	27	11	10
7	21	84	43	17	24
8	33	93	62	29	44
9	51	97	78	50	69
10	73	99	93	76	93

Source: The BILD Life Experiences Checklist Manual (Ager, 1998)

These data indicate that on the home subsection, 33% of the population would score below 8 and 51% would score below 9. Thus the community group mean score of 8.5 approached 'average' public scores. However, only 11% of the population would score below 6, which suggested that the home circumstances of the hospital residents were relatively impoverished, as they would be encountered by approximately one tenth of the population only.

On the leisure subsection, half of the population would be expected to score below 5 and one third would be expected to score below 4. Therefore the community group mean score of 3.8 indicated that community clients were experiencing fewer than average leisure activities, despite their presence in the community. However, the hospital group mean score of 2 reflected a considerably lower level of leisure activities, as only 6% of the population would score below this figure.

On the relationships subsection, the 'average' score for the population falls between 7 and 8, which was the level of the mean score of the current study general public group also. The impoverishment of both groups of adults with intellectual disabilities was evident in this domain, as the community group mean score was 5.4 and only 27% of the population would score below 6; and the hospital group mean score was 4.8 and only 17% of the population would score below 5.

On the freedom subsection, the lack of choice and autonomy experienced by the adults with intellectual disabilities was most evident. Half of the population would be expected to score below 9 on this domain (again the mean score achieved by the current general public group). However, the community group mean score was less than 6, which indicated a relative lack of freedom experienced by only 11% of the population; and the hospital group mean score was less than 3, which suggested a level of control by others experienced by only 1% of the population.

On the opportunities subsection, 44% of the population would be expected to score below 8, which indicated that the general public group experienced approximately average levels of opportunities. However, the community group mean score was less than 6, which indicated a relative lack of opportunities experienced by only 10% of the population; and the hospital group mean score was approximately 3, which reflected an opportunity deficiency experienced by only 1% of the population.

The centile distribution of total scores is reproduced in Table 10.15. As shown, 44% of the population would be expected to achieve a total LEC score below 35, and 51% would be expected to achieve a total score below 36, which suggested that the current study general public group had an above average range of life experiences overall, as only 32% of the population would be expected to score higher.

Table 10.15: Centile Distribution of LEC Total Scores for General Population Reference Sample (*N*=410)

Total Score	Centile Score	Total Score	Centile Score	Total Score	Centile Score
0 - 14		26	8	38	63
15	1	27	10	39	68
16	1	28	14	40	74
17	1	29	17	41	79
18	1	30	20	42	84
19	2	31	23	43	88
20	2	32	28	44	93
21	3	33	35	45	95
22	4	34	38	46	98
23	5	35	44	47	99
24	5	36	51	48	99
25	7	37	58	49 - 50	

Source: The BILD Life Experiences Checklist Manual (Ager, 1998)

However, both groups of adults with intellectual disabilities compared very unfavourably with the general population as only 17% would be expected to score below the level of the community group with a mean total score of 29; and only 2% would be expected to score below the level of the hospital group with a mean total score of 19.

Summary

The LEC scores of the hospital residents and community clients suggested that the two groups of adults with intellectual disabilities had a more limited range of experiences and opportunities than the general public group and the general population reference sample. Only in the home subsection were the scores of the community clients similar to that of the general public overall. In other domains, the general trend of scores indicated the community clients' relative lack of life experiences, and the hospital residents' more serious impoverishment of life experiences, particularly in respect of relationships, freedom and opportunities.

The differences between the main study groups, in terms of overall life experiences, were demonstrated clearly when the LEC total scores were aggregated into score bandings, as presented in Table 10.16.

This shows that 61% of hospital residents achieved total scores below 20 on the LEC, a level of score not shown by any community client and only one (0.5%) member of the public. In contrast, 55% of the public achieved a total score of 40 or more, a level of score not achieved by any hospital resident and only one (0.5%) community client. Within the middle range of scores, similar proportions of community clients (47%) and general public (42%) scored between 30 and 39, but this score band was achieved by only four hospital residents (2%).

Table 10.16: LEC Total Scores by Group

Group	*N*	LEC Total Score Bandings							
		0 - 19		20 - 29		30 - 39		40 +	
		N	%	*N*	%	*N*	%	*N*	%
Hospital	213	130	61.0	79	37.1	4	1.9	0	0.0
Community	204	0	0.0	107	52.5	96	47.1	1	0.5
General Public	208	1	0.5	6	2.9	87	41.8	114	54.8

Range of scores: 0 - 50

At this preliminary level of analysis, a 3*4 chi-square test was carried out to test the overall differences between the groups. This confirmed that there was a significant difference between the three main study groups on the basis of these aggregated score bandings ($\chi^2 = 644.660$, $df = 6$, $p < 0.001$).

Subsequently, more sophisticated analyses of the LEC subsection and total scores were carried out in order to explore the direction of differences between the hospital, community and general public groups in greater detail.

Between Groups Analysis

A series of three level between-groups analyses of variance were carried out to test for differences between the group means in relation to the LEC subsection and total scores. One of the key assumptions of ANOVA is homogeneity, or at least similarity, of variance. As the standard deviations presented with the group means in Table 10.13 suggested that the variance of some LEC subsection scores differed across the groups, the variances were inspected first.

Table 10.17: Variance of Subsection and Total Scores for Participant Groups

Group	*N*	Home	Leisure	Relationships	Freedom	Opportunities	LEC Total
Hospital	213	2.21	1.50	1.17	1.62	3.30	22.38
Community	204	0.63	2.98	1.10	2.16	2.43	19.31
General Public	208	1.44	3.82	4.01	1.46	1.56	25.65

However, as shown in Table 10.17, the greatest difference in variance was found on the Home and Relationships subsections, but in both cases the largest variance was less than four times the smallest (differing by factors of 3.51 and 3.65 respectively) and ANOVA is regarded as robust to this degree of difference in variance where groups are approximately equal in size (Clark-Carter, 1997).

The LEC item scores were derived from a dichotomous yes/no response scale, with subsection and total scores obtained by summing positive responses for the appropriate set of items. For the purpose of the analysis of variance, the underlying assumption was that these dichotomised responses reflected points on a continuous dimension i.e. were part of a continuous scale.

The statistics obtained from the results of the analyses of variance are summarised in Table 10.18.

Table 10.18: Analysis of LEC Subsection and Total Scores

Subsection	Mean (*SD*)			ANOVA		Post Hoc Comparisons	
	Hospital ^{H}	Community ^{C}	Public ^{P}	F 2, 622	$P <$	Test	$P < 0.05$
Home	6.00 (±1.48)	8.54 (± 0.79)	9.07 (± 1.20)	395.49	0.001	DC	H < C < P
Leisure	1.98 (± 1.23)	3.77 (± 1.73)	5.82 (± 1.96)	282.24	0.001	DC	H < C < P
Relationships	4.83 (± 1.08)	5.37 (± 1.05)	7.44 (± 2.00)	189.51	0.001	DC	H < C < P
Freedom	2.62 (± 1.27)	5.75 (± 1.47)	9.00 (± 1.21)	1228.75	0.001	DC	H < C < P
Opportunities	3.08 (± 1.82)	5.82 (± 1.56)	7.94 (± 1.25)	513.30	0.001	DC	H < C < P
LEC Total	18.51 (± 4.73)	29.24 (± 4.39)	39.27 (± 5.06)	1010.33	0.001	S	H < C < P

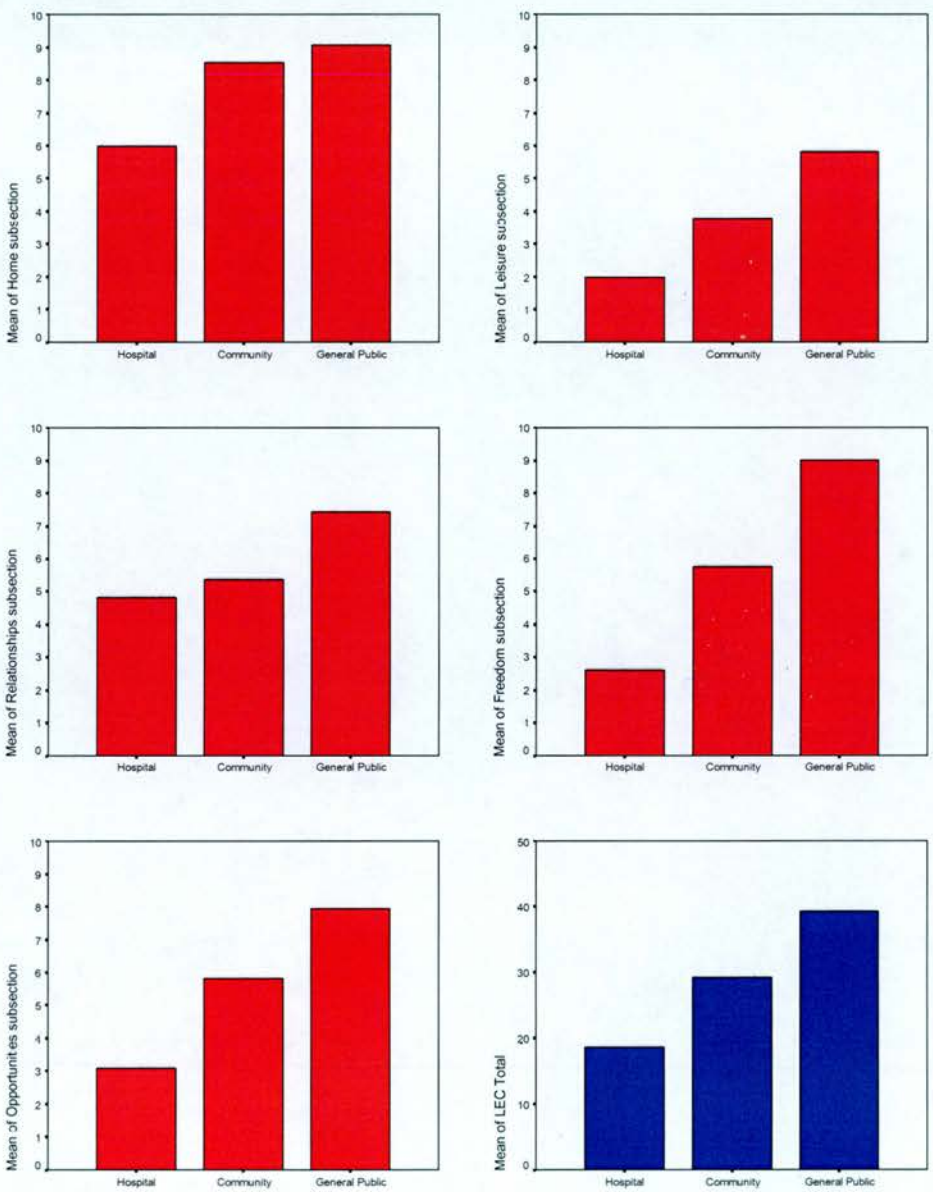
DC: Dunnett C (variances ≠) S: Scheffé (variances =)

As shown in Table 10.18, significant differences were found between the groups on all LEC subsections and for the total LEC scores ($F_{2, 622}$ with values ranging from 189.51 to 1228.75, $p < 0.001$). Therefore, post hoc comparisons were conducted to examine the source and direction of these differences.

Two different methods of post hoc comparison were employed as preliminary homogeneity of variance tests indicated that the variances of the group total scores were equal, but the variances of the group subsection scores were unequal. The tests selected for use were Scheffé (equal variances) and Dunnett C (unequal variances). These tests are regarded as representing conservative approaches, as they reduce the likelihood of a Type I error (in which a true null hypothesis is rejected), by increasing the possibility of a Type II error (in which a true research hypothesis is rejected), such that only very robust effects will produce significant results; and as unplanned comparisons, they are essentially exploratory, and hence only conducted when a statistically significant F-ratio is obtained (Clark-Carter, 1997). Within the context of SPSS (Windows) software (Version 11), the Scheffé test provides detailed differential significance levels for each set of comparisons, as well as indicating all comparisons which reach a criterion level of significance set at $p < 0.05$; however, the Dunnett C test only provides the latter output. Therefore this common approach was adopted in the presentation of the post hoc comparison results shown in the right hand column of Table 10.18.

For all the LEC subsection and total scores, significant differences were found at the level of 0.05 or better, in relation to every set of group comparisons i.e. hospital v community; community v general public; and hospital v general public. In addition, as shown in Figure 10.1, the direction of all significant differences on the subsection and total scores was uniform, with the mean score of hospital residents being significantly lower than that of community clients; and the mean score of community clients being significantly lower than that of the general public.

Figure 10.1: LEC Subsection and Total Score Means Plots



In relation to the set of life experiences measured by the LEC subsections, these results indicated that the adults with intellectual disabilities in the community had superior home circumstances, participated in more leisure activities, experienced enhanced relationships, encountered greater freedom and benefited from more opportunities than their counterparts in a hospital setting. However, in comparison with their general public counterparts living in similar community localities, their life conditions and range of life experiences remained relatively more impoverished and restricted.

The global measure of objective quality of life obtained from the LEC total score showed similar significant differences between the three groups, which indicated that the overall quality of life of community clients was superior to that of hospital residents; but the overall quality of life of the general public remained superior to that of both hospital residents and community clients.

As shown in Table 10.18 and Figure 10.1, the relative differences between all three groups in the current study were most marked in the domains of freedom and opportunities; and the relative differences between the hospital and community groups were most apparent in the domains of home, freedom and opportunities. These findings are reasonably consistent with those of other studies using the same instrument[6] with similar samples of adults with intellectual disabilities in hospital and community settings. However, some interesting differences emerge, as illustrated in Table 10.19.

Table 10.19: Comparison of Hospital and Community Group Mean LEC Subsection and Total Scores with Data from other Studies

Group	*N*	Home	Leisure	Relationships	Freedom	Opportunities	LEC Total
Hospital Residents							
Current study	213	6.0 (± 1.5)	2.0 (± 1.2)	4.8 (± 1.1)	2.6 (± 1.3)	3.1 (± 1.8)	18.5 (± 4.7)
Look (1987)	48	6.3 (± 1.4)	2.6 (± 1.5)	4.0 (± 1.2)	5.3 (± 1.4)	4.8 (± 1.5)	22.5 (± 4.7)
Community Clients							
Current study	204	8.5 (± 0.8)	3.8 (± 1.7)	5.4 (± 1.1)	5.8 (± 1.5)	5.8 (± 1.6)	29.2 (± 4.4)
Ager et al (1997, 2001)*	75	8.6	4.2	4.5	6.4	7.0	30.8
Current study follow up	60	8.6 (± 0.7)	4.1 (± 1.8)	5.3 (± 1.0)	6.4 (± 1.2)	6.0 (± 1.5)	30.7 (± 4.4)

* *SD* not reported

In a study of 48 hospital residents, Look (1987) found similar mean scores for the home, leisure and relationships subsections; but in his hospital sample the mean scores were higher than found in the current study hospital group for both freedom (approximately two standard deviations difference) and opportunities

[6] The most recent version of the BILD Life Experiences Checklist Manual (Ager, 1998) reports summary descriptive statistics from nine individual researchers or research groups.

(approximately one standard deviation difference). The characteristics of the 1987 sample[7] may have differed from those of the current hospital cohort; however, in the context of the similar mean scores in other domains, it is possible that the current hospital group were exposed to various restrictions within the framework of the resettlement and hospital closure programmes which had resulted in the closure of some wards, and limitations on some services, at the time of the study (staff shortages and staff rotating to cover unfamiliar wards leading to fewer residents attending day services or participating in community visits).

In a study of 75 community clients who were assessed during 1996/97, six to nine months post discharge, Ager et al (1997, 2001) found similar mean scores for home, leisure and freedom. Although, in their community sample, a lower mean score was found for relationships (-0.9, *SD* not reported) and a higher mean score was found for opportunities (+1.2, *SD* not reported) compared with the current study community cohort. However, 60 individuals within this sample of community clients were part of the current study community group also; and for this subset of individuals, the mean LEC scores measured on the second occasion (some four to five years later) as part of the current research were consistent with those found for the present study community cohort as a whole. Caution should be be exercised in interpreting this finding, as these individuals represented an overlapping subset of participants between the two studies only. However, the small positive change in the mean score on relationships demonstrated for this group may have reflected the development of some aspects of social relationships over time, perhaps as individuals became more established in their local neighbourhoods; and the negative change in the mean score on the opportunities subsection tended to suggest either that the immediate post resettlement assessments reflected a 'honeymoon' element associated with the change of environment, or that client participation in (or possibly staff support for) the contextual opportunities afforded by community life may have declined. This finding demonstrates that achievement of community presence for a service and its residents may not be sufficient to provide consistent life experiences, and highlights the need for routine service quality assurance and regular monitoring of individuals' quality of life.

Response Mode Analysis

Of the combined group of adults with intellectual disabilities, 74 participants (18%) responded directly to the LEC items and staff proxies responded on behalf of the remaining 343 participants (82%). A series of independent samples *t*-tests were used to analyse the mean LEC subsection and total scores for these two subgroups to test for differences associated with response mode.

[7] These data were reported originally as part of a Masters Thesis, a copy of which was requested from the University of Birmingham, but could not be found.

Table 10.20: Variance of Subsection and Total Scores by Response Mode

Subgroup	*N*	%	Home	Leisure	Relationships	Freedom	Opportunities	LEC Total
Direct	74	17.7	3.01	3.70	1.09	3.49	3.15	40.36
Proxy	343	82.3	2.92	2.63	1.16	3.93	4.08	43.19

As shown in Table 10.20, the numbers in the two subgroups were unequal (although reasonably large), but the subsection and total score variances were sufficiently similar for the key assumption of homogeneity of variance to be met (in all cases the larger variance being considerably less than three times the smaller variance) and therefore it was legitimate to use a *t*-test to compare the means of the two groups, as the test remains sufficiently robust in these circumstances (Clark-Carter, 1997).

The statistics obtained from the results of the *t*-tests are summarised in Table 10.21. Significant differences were found between the direct and proxy subgroups on all LEC subsections and for the total LEC score. For the home, leisure, relationships and freedom subsections, and for the LEC total, *t* values between 4.205 and 8.316 were obtained (all $df = 415$, $p < 0.001$, two-tailed, variances equal); and for the opportunities subsection, the *t* value was 10.281 ($df = 117.558$, $p < 0.001$, two-tailed, variances unequal).

Table 10.21: Analysis of LEC Subsection and Total Scores by Response Mode

Subsection	Mean (*SD*)		*t*- test (2- tailed)			
	Direct (*N* = 74)	Proxy (*N* = 343)	*t*	*P* <	*df*	Variances
Home	8.00 (± 1.74)	7.08 (± 1.71)	4.205	0.001	415	=
Leisure	3.84 (± 1.92)	2.64 (± 1.62)	5.549	0.001	415	=
Relationships	5.61 (± 1.04)	4.98 (± 1.08)	4.550	0.001	415	=
Freedom	5.65 (± 1.87)	3.83 (± 1.98)	7.249	0.001	415	=
Opportunities	6.39 (± 1.71)	3.99 (± 2.02)	10.281	0.001	117.558	≠
LEC Total	29.49 (± 6.35)	22.52 (± 6.57)	8.316	0.001	415	=

The direction of all the significant differences on the subsection and total scores was uniform, with the mean score of proxy respondents being significantly lower than that of direct respondents. These findings suggested that the adults with intellectual disabilities who responded directly to the LEC had superior home circumstances, participated in more leisure activities, experienced enhanced relationships, encountered greater freedom and benefited from more opportunities than those for whom staff proxy responses were obtained; and enjoyed a superior overall quality of life also.

However, as decisions about response mode were led by staff advice about the capacity of each ID client to participate directly or not (adjudicated by the principal researcher where doubt existed), it was necessary to explore the relationship between response mode and overall level of dependency also.

Table 10.22 shows the proportion of direct client and proxy staff respondents by level of ID client dependency on the Degree of Dependency Rating Scale (DDRS), according to the more robust aggregation[8] of categories described in Chapter 8. A 3*2 chi-square test was carried out on this contingency table and a significant difference was found between the response mode subgroups on the basis of these aggregated categories of dependency ($\chi^2 = 133.807$, $df = 2$, $p < 0.001$). This indicated that the clients responding directly to the assessment tended to be of lower dependency than those for whom staff acted as proxies.

Table 10.22: Response Mode by Level of Dependency (1) DDRS Aggregated Categories

Dependency Level (DDRS)	Response Mode			
	Direct (*N* = 74)		Proxy (*N* = 343)	
	N	%	*N*	%
Low	45	63.4	26	7.6
Moderate	16	22.5	92	27.0
High	10	14.1	223	65.4
	71	100.0	341	100.0

Missing cases: Direct = 3 Proxy = 2

Similarly, as shown in Table 10.23, a significant difference was found between the mean weighted[9] Dependency and Needs Information System (DANIS) scores for the direct and proxy subgroups ($t = 4.819$, $df = 306$, $p < 0.001$, two-tailed, variances equal), confirming the relationship between response mode and level of dependency.

Table 10.23: Response Mode by Level of Dependency (2) Weighted DANIS

Mean (*SD*)		*t*- test (2- tailed)			
Direct (*N* = 74)	Proxy (*N* = 343)	*t*	*P* <	*df*	Variances
0.89 (± 0.22)	1.05 (± 0.21)	4.819	0.001	306	=

Missing cases: Direct = 25 Proxy = 84

[8] A chi-square test was attempted on the full nine DDRS categories, but some cells were found to have low expected frequencies (22.2% of cells with a count < 5) and the resulting chi-square statistic was likely to be an overestimate and therefore unreliable.

[9] Lower weighted scores indicative of lower dependency.

The implication of these results, taken together with the significant differences in mean LEC subsection and total scores found for the direct and proxy subgroups, suggested that clients with lower levels of dependency enjoyed a wider range of life experiences, and a higher quality of life overall, than clients with higher dependency.

This was explored further by investigating the pattern of inter-subsection correlations and subsection-total correlations for the LEC (Pearson's *r*), and the relationship between these scores and the weighted DANIS scores (Pearson's *r*) and nine DDRS categories (Spearman's rho), as shown in Table 10.24.

Table 10.24: Correlations of LEC Scores and Dependency Measures

LEC & Dependency	Corr.	*N*	Home	Leisure	Relation.	Freedom	Opport.	Total	DANIS	DDRS
Home	*r*	417	1.0							
Leisure	*r*	417	0.5**	1.0						
Relationships	*r*	417	0.4**	0.3**	1.0					
Freedom	*r*	417	0.7**	0.6**	0.3**	1.0				
Opportunities	*r*	417	0.6**	0.6**	0.3**	0.8**	1.0			
LEC Total	*r*	417	0.8**	0.8**	0.5**	0.9**	0.9**	1.0		
Weighted DANIS	*r*	308	-0.1*	-0.1*	-0.2**	-0.3**	-0.3**	-0.3**	1.0	
DDRS Categories	rho	412	-0.2**	-0.1**	-0.1*	-0.2**	-0.3**	-0.3**	0.4**	1.0

Missing cases: DANIS = 109 (4 hospital, 105 community) DDRS = 5 (community)
** Significant at 0.01 level (2-tailed) * Significant at 0.05 level (2-tailed)

In relation to inter-subsection scores, low to moderate positive correlations were found between leisure and relationships, between relationships and freedom and between relationships and opportunities ($r = 0.3, p < 0.01$); moderate correlations were found between home and relationships ($r = 0.4$, $p < 0.01$) and between home and leisure ($r = 0.5$, $p < 0.01$); and high positive correlations were found between home and opportunities, leisure and freedom, leisure and opportunities ($r = 0.6$, $p < 0.01$), and between home and freedom ($r = 0.7$, $p < 0.01$); and the strongest positive correlation was found between the freedom and opportunities subsections ($r = 0.8, p < 0.01$).

For subsection-total scores, a moderate positive correlation was found between relationships and the LEC total ($r = 0.5, p < 0.01$); and high positive correlations were found between the remaining subsections (home, leisure, freedom and opportunities) and the LEC total (r values from 0.8 to 0.9, $p < 0.01$).

However, the pattern of correlations between the two dependency measures (which correlated moderately, rho = 0.4, $p < 0.01$) and the LEC subsection and total scores showed relatively weak negative associations only (r and rho values ranging from 0.1 to 0.3, $p < 0.05$ to $p < 0.01$).

This suggested that differential levels of dependency might not account fully for the differential quality of life outcomes found for the direct and proxy subgroups on the LEC.

Partial correlations between the LEC scores and dependency were carried out to control for the effect of direct or proxy response mode. As shown in Table 10.25, extremely low non-significant negative correlations ($r < -0.1$) were found between both dependency measures and the home, leisure and relationships subsections; and only very low significant negative correlations between dependency and the freedom and opportunities subsections ($r \leq -0.2$), and between dependency and the LEC total ($r < -0.2$), the latter being accounted for by the high positive correlation ($r = 0.9$) between these two subsections and the total score shown in Table 10.24. These findings confirmed that the level of dependency of the adults with intellectual disabilities did not impact strongly on the life experiences measured by the LEC domains of home, leisure and relationships; and had a weak association only with scores on the LEC domains of freedom and opportunities.

Table 10.25: Partial Correlations of LEC Scores and Dependency Measures (controlling for Response Mode)

Dependency	*df*	Home	Leisure	Relationships	Freedom	Opportunities	Total
Weighted DANIS	305	-0.08	-0.06	-0.09	-0.16**	-0.21**	-0.17**
DDRS Categories[10]	409	-0.06	-0.04	-0.03	-0.16**	-0.14**	-0.12*

Missing cases: DANIS = 109 (4 hospital, 105 community) DDRS = 5 (community)
** Significant at 0.01 level (2-tailed) * Significant at 0.05 level (2-tailed)

This suggested that the significantly lower LEC subsection and total scores obtained by clients for whom proxy responses were provided (compared to the scores of those who responded directly) might be related to the *perceptions* of proxy staff about the individuals' life experiences. This finding is congruent with social comparison theory, which describes the mechanisms by which people evaluate themselves in relation to others (Festinger, 1954). Staff proxies may have been making 'downwards' social comparisons, accentuating the differences between themselves and their clients, reinforcing their own self esteem and perceived superiority to the adults with intellectual disabilities (as a low status or societal 'out-group'), enhancing their evaluation of their own life quality, but also depressing the scores assigned to certain facets of the life experience of the clients rated. In essence the schema of staff proxies may have been 'I must be better off than this person who is...intellectually disabled, mentally disordered, lacking capacity ...' and hence, 'if I were this person I would not/could not do this, or enjoy that...and therefore it must be that they do not/cannot do this or enjoy that...'

[10] Assumed to be a continuous scale for the purpose of conducting the partial correlation.

10.2 Subjective Quality of Life

All 625 participants completed the second quality of life measure, the WHOQOL. As shown in Table 10.26, a total of 520 participants, 417 adults with intellectual disabilities in the hospital and community groups, and 103 members of the general public, were presented with the WHOQOL-ID; and 105 members of the general public were presented with the WHOQOL-BREF.

Table 10.26: WHOQOL Completion by Participant Group, Response Mode and Version

Response Mode	Hospital (*N* = 213)		Community (*N* = 204)		Public (*N* = 103)		Public (*N* = 105)	
	WHOQOL-ID		WHOQOL-ID		WHOQOL-ID		WHOQOL-BREF	
	N	%	*N*	%	*N*	%	*N*	%
Direct Interview	28	13.1	46	22.5	-	-	-	-
Proxy Interview	185	86.9	158	77.5	-	-	-	-
Postal Self Completion	-	-	-	-	103	100.0	105	100.0

As described for the first quality of life measure, the LEC, a total of 74 ID clients participated directly in the setting of an interview (13% of the hospital residents and 23% of the community clients); 343 proxy staff responded on behalf of ID clients (87% for hospital residents and 76% for community clients); and 208 members of the general public returned the self-completed measure by post.

In contrast to the LEC, all participants did not complete every WHOQOL item, but the rate of missing values was very low at 0.8% (see Chapter 9), which suggested that most participants found the wording of items straightforward and unambiguous, and the subject matter of acceptable sensitivity.

Inter-Rater Reliability

In relation to the adults with intellectual disabilities, two researchers (the principal researcher and a research assistant) were involved in the interviews during which the client, or their proxy key worker, completed the WHOQOL-ID. However, as respondents were asked to indicate the scale point that reflected their response to each item (i.e. providing a direct and unambiguous answer, rather than one subject to interviewer judgement or interpretation, and hence potential bias) inter-rater reliability procedures were not undertaken for this measure.

Between Groups Analysis of Facets

A series of three level between-groups analyses of variance were carried out to test for differences between the group means in relation to the 35 WHOQOL facet scores[11].

One of the key assumptions of ANOVA is homogeneity, or at least similarity, of variance. The standard deviations presented with the facet means in Table 10.27 suggested that the facet scores had similar variance, however, this was confirmed prior to proceeding. The larger variance on all facets was found to be less than three times the smaller variance, except for one facet where the variance differed by a factor of 3.19 (as shown in Table A10.1 in Appendix 10) and ANOVA is regarded as robust to this degree of difference in variance where groups are approximately equal in size (Clark-Carter, 1997).

For the original WHOQOL-100, facet scores are derived from sets of four related items (see Chapter 4). However, for the abbreviated version of the instrument, the WHOQOL-BREF, and hence the adapted WHOQOL-ID, single items represent each facet, and thus facet scores are derived directly from the five point Likert response scales. For the purpose of the analysis of variance, these scores were treated as interval data on continuous scales.

The statistics obtained from the results of the analyses of variance are summarised in Table 10.27, presented according to the original WHOQOL-BREF domain structure supplemented by the new ID module.

Significant differences were found between the three groups on twenty-eight of the item-facets distributed across all domains (with F values ranging from $F_{2, 620} = 3.177$, $p < 0.05$, to $F_{2, 619} = 197.013$, $p < 0.001$); and non-significant results were found on the remaining seven item-facets. The distribution of significant and non-significant results are summarised by domain in Table 10.28.

Post hoc comparisons were conducted to examine the source and direction of the significant differences found on these 28 items. Two different methods of post hoc comparison were employed, as the preliminary homogeneity of variance tests indicated that the variances of eight facet scores were equal, but the variances of twenty facet scores were unequal. The rationale for selection of the two tests, Scheffé and Dunnett C, as conservative approaches producing significant results for robust effects only, was described fully in section 10.1 in relation to the LEC, as was the common approach adopted to the presentation of the post hoc comparison results from both tests (indicating all comparisons which reach a criterion level of significance set at $p < 0.05$).

[11] Facet 34 (advocacy) was excluded from all analyses subsequent to the findings of poor psychometric performance outlined in Chapter 9.

Table 10.27: Analysis of WHOQOL Facets

Domain Facet		Mean (*SD*)			ANOVA		Post Hoc Comparisons	
		Hospital H	Community C	Public P	*F**	*P* <	Test	*P* < 0.05
General								
1	Overall QOL	3.81 (± 0.93)	4.12 (± 0.85)	4.11 (± 0.95)	7.728	0.001	S	H < C = P
2	General health	3.78 (± 0.97)	3.80 (± 0.94)	3.75 (± 1.00)	0.160	NS	-	-
3	Pain	3.99 (± 1.20)	4.12 (± 1.05)	4.12 (± 0.99)	1.109	NS	-	-
4	Medication	2.69 (± 1.19)	2.87 (± 1.16)	3.96 (± 1.22)	69.328	0.001	S	H = C < P
10	Energy	3.75 (± 0.95)	3.61 (± 1.01)	3.85 (± 0.96)	3.177	0.05	S	C < P, H = C, H = P
15	Mobility	3.18 (± 1.53)	3.65 (± 1.49)	4.49 (± 0.86)	51.860	0.001	DC	H < C < P
16	Sleep	4.29 (± 0.71)	4.33 (± 0.87)	3.57 (± 1.11)	45.488	0.001	DC	H = C < P
17	ADL	3.63 (± 0.96)	3.74 (± 0.99)	4.19 (± 0.92)	20.141	0.001	S	H = C < P
18	Work	3.60 (± 0.95)	3.97 (± 0.84)	4.10 (± 0.97)	16.638	0.001	DC	H < C = P
Psychological								
5	Positive feelings	3.70 (± 0.83)	4.00 (± 0.81)	4.09 (± 0.77)	13.742	0.001	S	H < C = P
6	Spirituality	1.31 (± 0.86)	1.51 (± 1.07)	3.25 (± 1.31)	197.013	0.001	DC	H = C < P
7	Thinking	2.36 (± 1.24)	2.23 (± 1.09)	3.92 (± 0.88)	156.476	0.001	DC	H = C < P
11	Body image	3.54 (± 1.00)	3.59 (± 0.94)	3.61 (± 1.09)	0.244	NS	-	-
19	Self esteem	3.67 (± 0.91)	3.90 (± 0.84)	3.94 (± 0.90)	4.221	0.01	S	H < C = P
26	Negative feelings	3.20 (± 0.86)	3.10 (± 0.72)	3.46 (± 0.83)	10.989	0.001	DC	H = C < P
Social								
20	Personal relationships	3.58 (± 0.88)	3.77 (± 0.93)	4.27 (± 0.82)	33.477	0.001	S	H = C < P
21	Sexual/special relationship	3.83 (± 0.84)	4.22 (± 0.78)	4.06 (± 1.03)	10.242	0.001	DC	H < C = P
22	Social support	3.97 (± 0.62)	4.38 (± 0.72)	4.18 (± 0.84)	16.826	0.001	DC	H < P < C
Environment								
8	Safety	4.00 (± 0.90)	4.25 (± 0.93)	4.17 (± 0.76)	4.234	0.05	DC	H < C, P = H, P = C
9	Physical environment	3.67 (± 0.92)	4.06 (± 0.88)	3.97 (± 0.81)	10.223	0.001	DC	H < C = P
12	Finance	3.83 (± 0.91)	3.96 (± 0.97)	3.82 (± 1.01)	1.406	NS	-	-
13	Information	3.34 (± 1.28)	3.10 (± 1.52)	4.12 (± 0.76)	38.326	0.001	DC	H = C < P
14	Leisure activities	2.95 (± 1.27)	3.61 (± 1.04)	3.85 (± 0.99)	37.343	0.001	DC	H < C = P
23	Home	3.78 (± 0.89)	4.44 (± 0.80)	4.37 (± 0.79)	39.515	0.001	S	H < C = P
24	Health/social care	4.00 (± 0.64)	4.42 (± 0.70)	3.97 (± 0.84)	24.495	0.001	DC	H = P < C
25	Transport	3.69 (± 0.97)	4.06 (± 1.12)	4.20 (± 0.86)	15.296	0.001	DC	H < C = P
Social Inclusion								
27	Stigmatisation	4.44 (± 0.85)	4.53 (± 0.85)	4.50 (± 0.70)	0.723	NS	-	-
28	Victimisation	4.00 (± 0.99)	4.09 (± 1.05)	4.08 (± 0.80)	0.516	NS	-	-
29	Ridicule	4.35 (± 0.89)	4.54 (± 0.84)	4.65 (± 0.67)	7.261	0.01	DC	H < P, C = H, C = P
30	Discrimination	4.31 (± 0.93)	4.18 (± 1.06)	4.63 (± 0.66)	13.880	0.001	DC	H = C < P
35	Respect	3.71 (± 0.97)	3.98 (± 0.94)	3.97 (± 0.80)	5.683	0.01	DC	H < C = P
36	Acceptance	4.24 (± 0.80)	4.29 (± 0.84)	4.33 (± 0.65)	0.674	NS	-	-
Empowerment								
31	Enabling	3.70 (± 1.10)	3.83 (± 1.08)	4.17 (± 0.78)	12.058	0.001	DC	H = C < P
32	Empowerment	4.01 (± 0.95)	4.34 (± 0.81)	3.87 (± 0.75)	16.597	0.001	DC	H = P < C
33	Autonomy	3.57 (± 1.00)	3.85 (± 0.74)	3.91 (± 0.67)	10.093	0.001	DC	H < C = P

DC: Dunnett C (variances ≠) S: Scheffé (variances =) F^*: varies from $F_{2, 575 \text{ (item 9 only)}}$ to $F_{2, 621}$

Table 10.28: Summary of Significant and Non-Significant Differences on WHOQOL Facets

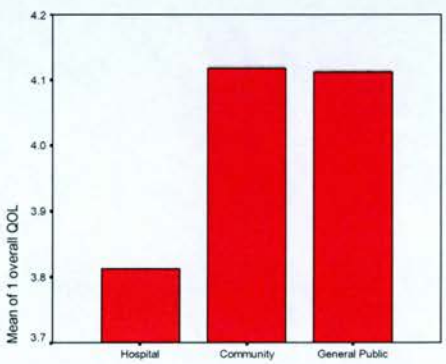
Model	Domain	Facets	Significant		Non-Significant	
		(*N* = 35)	*N*	%	*N*	%
General	General	2	1	50.0	1	50.0
BREF Model	Physical	7	6	85.7	1	14.3
	Psychological	6	5	83.3	1	16.7
	Social	3	3	100.0	0	0
	Environment	8	7	87.5	1	12.5
Supplementary ID Module	Social Inclusion	6	3	50.0	3	50.0
	Empowerment	3	3	100.0	0	0

General

The analysis of variance produced no significant difference between the hospital, community and general public groups on item 2 (general health). This was consistent with the finding that the participant groups were matched for health status (described in Chapter 8).

However, a significant difference was found on item 1 (overall quality of life). The subsequent post hoc comparisons demonstrated that there was a significant difference between the hospital and community groups ($p < 0.01$), and between the hospital and public groups ($p < 0.01$); but no difference was found between the community and public groups.

Figure 10.2: Means Plots for Overall Quality of Life (F1)



As shown in Table 10.27 and Figure 10.2, these findings indicated that both community clients and the public had a superior overall quality of life compared to hospital residents; and that community clients had achieved an overall quality of life similar to that of their non-intellectually disabled general population counterparts living in similar local neighbourhoods.

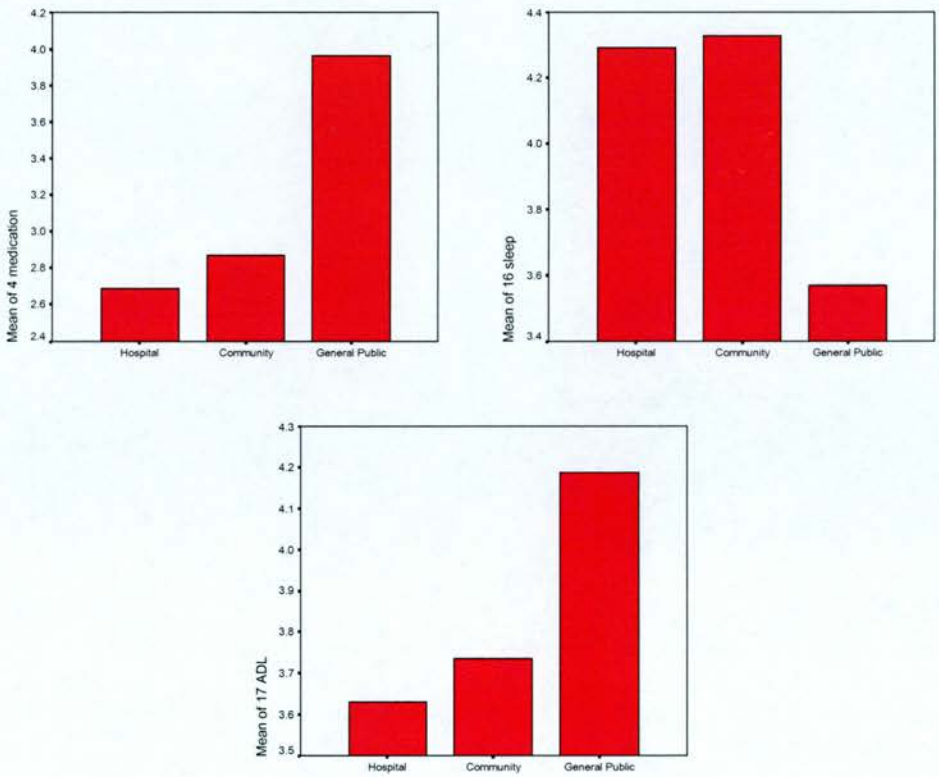
Physical

The analysis of variance produced no significant difference between the hospital, community and general public groups on item 3 (pain), which was consistent with the findings for the general health facet and for health status.

However, significant differences were found between the participant groups on items 4 (medication), 10 (energy), 15 (mobility), 16 (sleep), 17 (activities of daily life) and 18 (work).

On three items (medication, sleep and activities of daily life) the subsequent post hoc comparisons demonstrated that there was a significant difference between both groups of adults with intellectual disabilities and the public ($p < 0.05$ or better); but no difference was found between the hospital and community groups.

Figure 10.3: Means Plots for Medication (F4), Sleep (F16) and Activities of Daily Life (F17)



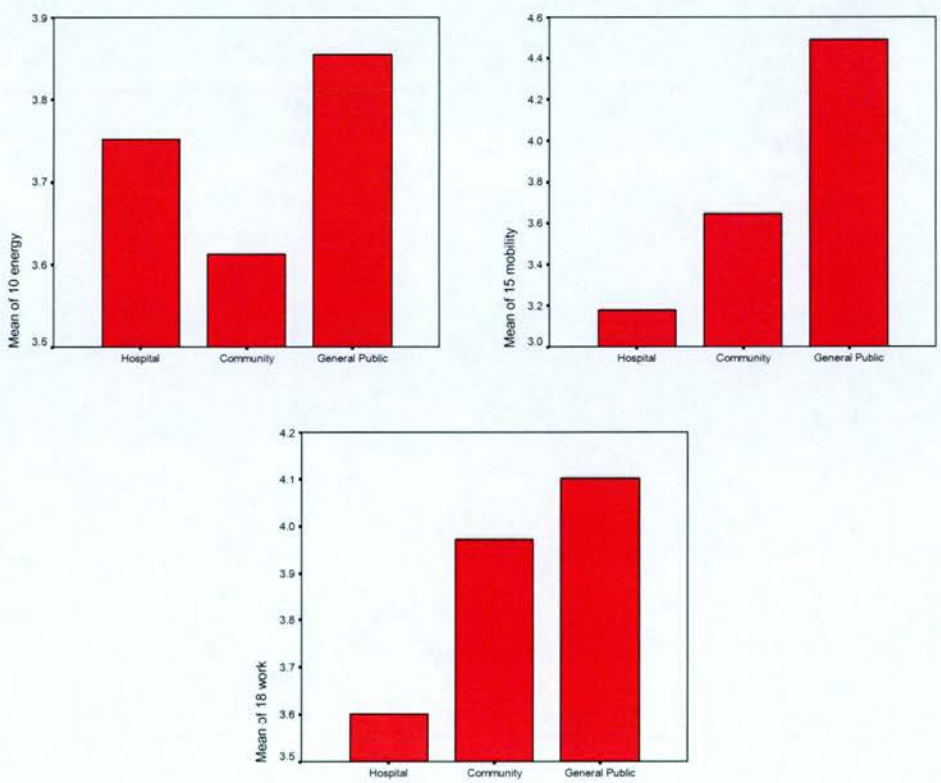
As shown in Table 10.27 and Figure 10.3, these findings indicated that the public required less medication[12] or medical treatments to function in their daily life, were less satisfied with their sleep (a finding which may have been linked to

[12] Negatively phrased, therefore scores reversed such that a higher score reflects less use of medication etc and thus a higher quality of life.

medication use in the other two groups, see Chapter 9), and were more satisfied with their ability to carry out activities of daily living than both the hospital and community groups; but despite their different locations, community clients and hospital residents continued to achieve similar mean scores on all these quality of life facets.

On the remaining three items (energy, mobility and work) the subsequent post hoc comparisons demonstrated a more varied pattern of significant differences. On the energy item, there was no significant difference between the hospital and community groups, or between the hospital and public groups; but a significant difference was found between the community and public groups ($p < 0.05$). On the mobility item, significant differences were found in relation to every set of group comparisons i.e. hospital v community, community v general public, and hospital v general public ($p < 0.05$). Finally, on the work item, significant differences were found between the hospital and community groups, and between the hospital and public groups ($p < 0.05$); but no difference was found between the community and public groups.

Figure 10.4: Means Plots for Energy (F10), Mobility (F15) and Work (F18)



As shown in Table 10.27 and Figure 10.4, in terms of energy, there were very small differences between the three groups, such that the public were more likely to indicate that they had enough energy for their daily life than community

clients, but the differences between hospital residents and community clients, and between hospital residents and the public were small and non-significant. However, in respect of mobility, hospital residents were less able to get around than community clients; and community clients were less able to get around than the general public. In relation to work, hospital residents were less satisfied with their work capacity than both community clients and the public; but community clients and the public demonstrated similar levels of satisfaction with their work capacity.

Psychological

The analysis of variance produced no significant difference between the hospital, community and public groups on item 11 (body image), which suggested that all participants had reported similar degrees of self-acceptance of their bodily appearance.

At one level this seemed a paradoxical finding, given that many of the adults with intellectual disabilities in the hospital and community groups had been observed to have physical disabilities (e.g. cerebral palsy, scoliosis), tardive dyskinesia (involuntary movements liked to various anti-psychotic medication), pronounced facial characteristics associated with Down's Syndrome, or obesity (from years of institutional diet and nutrition). The members of the general public may have experienced similar levels of physical or aesthetic problems, but this was unknown (as these participants were unmet). Alternatively, the clients with intellectual disabilities may have adopted a less superficial view of such matters, or participants in all three groups may have habituated to their particular appearance to similar extents.

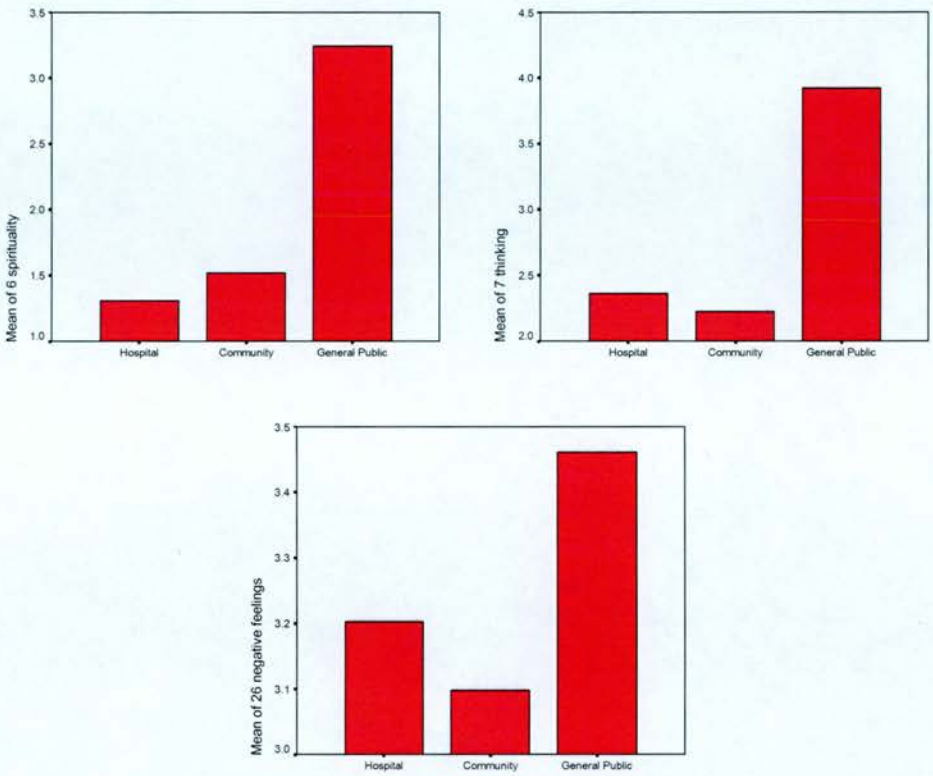
However, significant differences were found between the participant groups on items 5 (positive feelings), 6 (spirituality), 7 (thinking), 19 (self esteem) and 26 (negative feelings).

On three items (spirituality, thinking and negative feelings) the subsequent post hoc comparisons demonstrated that there was a significant difference between both groups of adults with intellectual disabilities and the public ($p < 0.05$); but no difference was found between the hospital and community groups.

As shown in Table 10.27 and Figure 10.5, these findings indicated that the public reported higher levels of spirituality, superior concentration, and less frequent negative feelings[13] than both the hospital and community groups; but community clients and hospital residents demonstrated similar mean scores on all these quality of life facets.

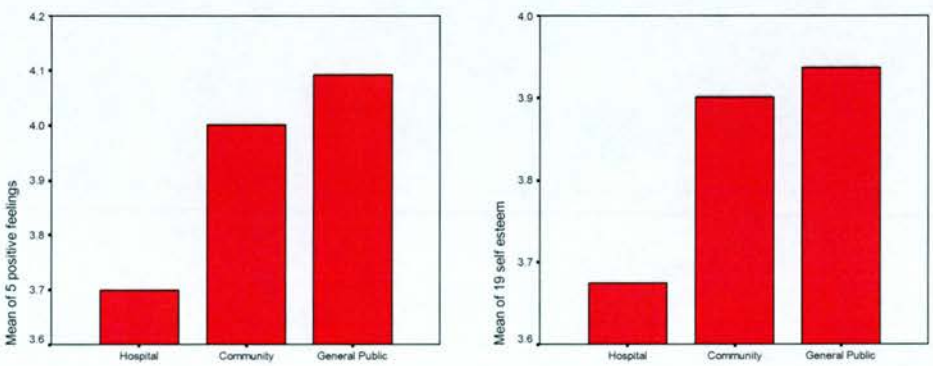
[13] Negatively phrased, therefore scores reversed such that a higher score reflects less frequent negative feelings and thus a higher quality of life.

Figure 10.5: Means Plots for Spirituality (F6), Thinking (F7) and Negative Feelings (F26)



On two items (positive feelings and self-esteem) significant differences were found between the hospital and community groups, and between the hospital and public groups ($p < 0.05$ or better); but no difference was found between the community and public groups.

Figure 10.6: Means Plots for Positive Feelings (F5) and Self Esteem (F19)

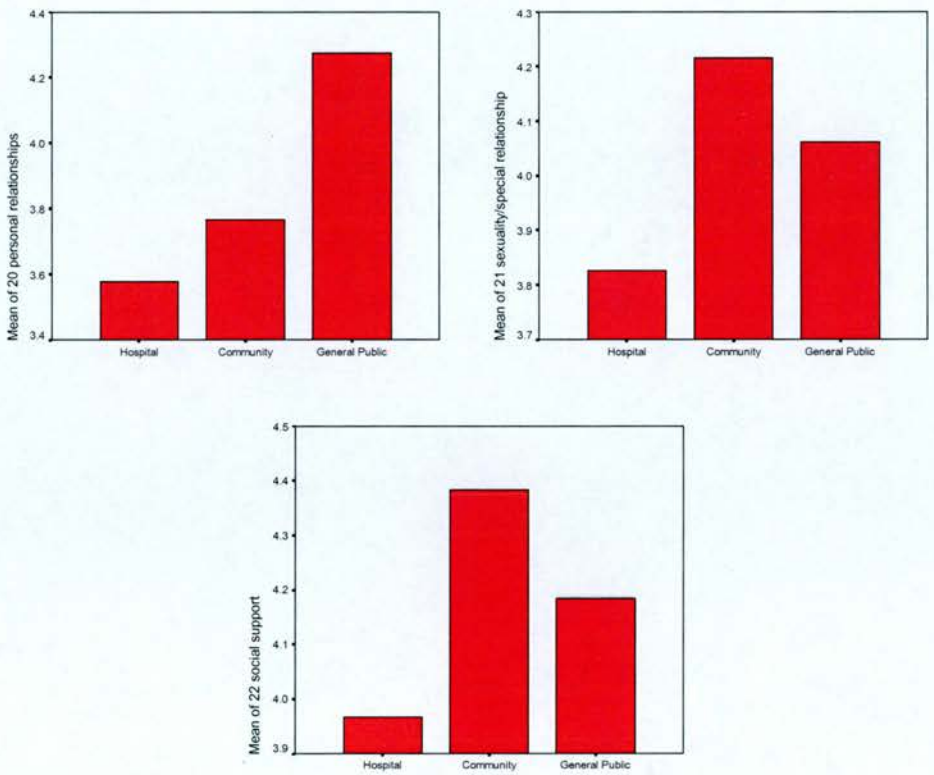


As shown in Table 10.27 and Figure 10.6, these findings indicated that hospital residents reported less enjoyment of life, and less satisfaction with themselves as people, than both community clients and the public; but that community clients and the public demonstrated similar levels of positive feelings about their lives and similar self esteem also, suggesting that community resettlement had enhanced significantly aspects of community clients' emotional well-being.

Social

Significant differences were found between the participant groups on all three social relationship items, but the source and direction of these differences varied for each item.

Figure 10.7: Means Plots for Personal Relationships (F20), Sexuality/Special Relationship (F21) and Social Support (F22)



On the first item (personal relationships) the subsequent post hoc comparisons demonstrated that there was a significant difference between both groups of adults with intellectual disabilities and the public ($p < 0.001$); but no difference was found between the hospital and community groups. On the second item (sexual activity/special relationship) significant differences were found between the hospital and community groups, and between the hospital and public groups ($p < 0.05$); but no difference was found between the community and public

groups. On the third item (social support), significant differences were found in relation to every set of group comparisons i.e. hospital v community, community v general public, and hospital v general public ($p < 0.05$).

As shown in Table 10.27 and Figure 10.7, these findings suggested that the general public were more satisfied with their personal relationships than both the hospital residents and community clients; but hospital and community groups demonstrated similar mean scores on this quality of life facet. In relation to the more sensitive sexual activity/special relationship item, community clients and the public demonstrated similar levels of satisfaction, but hospital residents were less satisfied with this aspect of their life. However, in respect of the social support item, community clients demonstrated the highest levels of satisfaction, being significantly more satisfied with the support provided by their friends than both hospital residents and the public, although the public reported more satisfaction with the support available from their social networks than hospital residents.

This latter finding was unexpected. If informal predictions about the social support item had been considered prior to the study, three alternative outcomes might have been hypothesised: *either* H < C < P; *or* H = C < P; *or* H < C = P. However, the current finding may be accounted for in terms of the prioritisation given to fostering high levels of social support by many of the small community projects in which these community clients resided.

Environment

The analysis of variance produced no significant difference between the hospital, community and public groups on item 12 (finance), which suggested participants had reported similar availability of enough money for day-to-day needs.

However, significant differences were found between the participant groups on items 8 (safety), 9 (physical environment), 13 (information), 14 (leisure activities), 23 (home), 24 (health/social care) and 25 (transport).

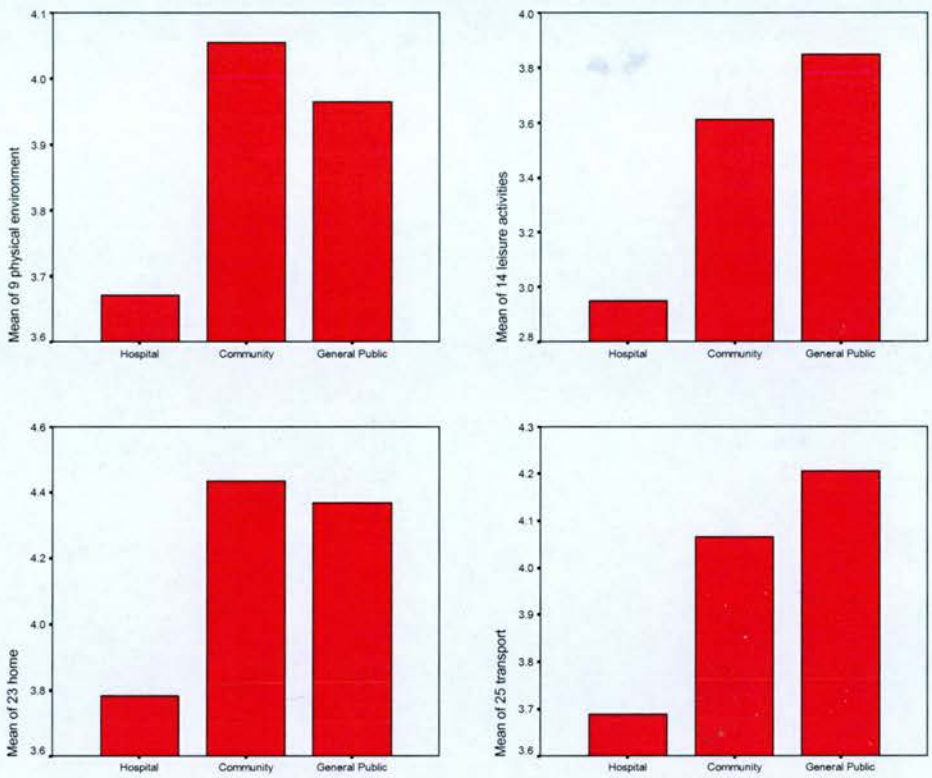
On four items (physical environment, leisure activities, home and transport) the subsequent post hoc comparisons indicated significant differences between the hospital and community groups, and between the hospital and public groups ($p < 0.05$ or better), but no difference was found between the community and public groups.

As shown in Table 10.27 and Figure 10.8, these findings suggested that hospital residents lived in less healthy physical environments, experienced fewer opportunities for leisure activities, reported less satisfaction with the conditions of the places they lived (mainly wards), and were less satisfied with the transport arrangements available to them than both community clients and the public; but that the community clients and the general public resided in similar physical environments (consistent with matching on the variable of locality), experienced

similar opportunities for leisure activities, and reported similar levels of satisfaction with their homes and transport.

Once again, these outcomes pointed to the impact of community resettlement in enhancing significantly the material conditions of community clients' lives, and widening the range of opportunities open to them in these new locations for non-work related activities.

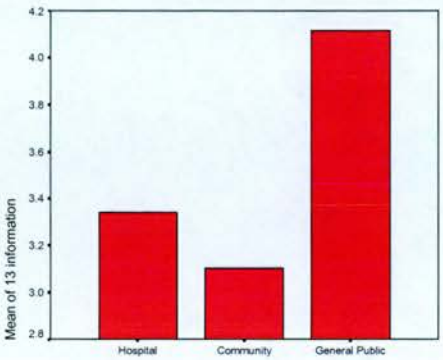
Figure 10.8: Means Plots for Physical Environment (F9), Leisure Activities (F14), Home (F23) and Transport (F25)



On one item (information) there was a significant difference between both groups of adults with intellectual disabilities and the public ($p < 0.05$); but no difference was found between the hospital and community groups.

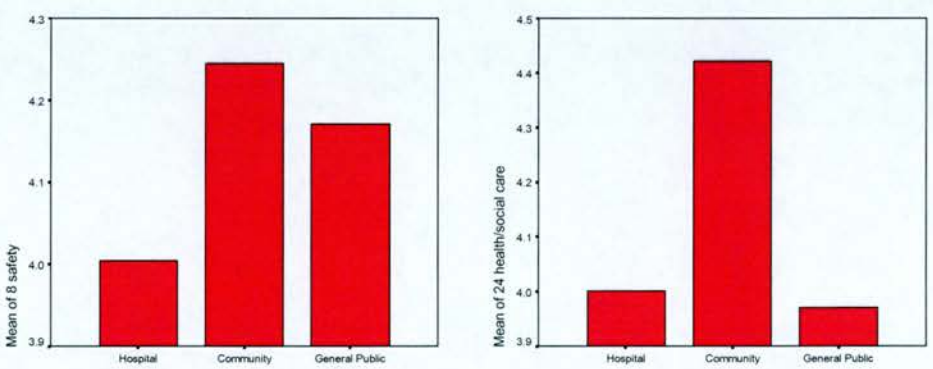
As shown in Table 10.27 and Figure 10.9, this finding indicated that the public reported superior availability of, or ease of access to, the type of information needed for their day-to-day lives compared to both the hospital and community groups; but community clients and hospital residents had similar levels of difficulty in accessing such information. This may be accounted for in terms of the overall dependency and level of cognitive functioning of many of the adults with intellectual disabilities; however it may reflect the 'need to know' basis on which information is imparted to cared-for individuals in many settings.

Figure 10.9: Means Plots for Information (F13)



On the remaining two items (safety and health/social care) the superior, and somewhat anomalous, situation of the community clients was demonstrated. In relation to safety, the post hoc comparisons demonstrated that there was no significant difference between the hospital residents and the public, or between the community clients and the public; but a significant difference was found between the hospital and community groups ($p < 0.05$). In respect of health/social care, there was no significant difference between the hospital and public groups, but a significant difference was found between the community clients and both other groups ($p < 0.05$).

Figure 10.10: Means Plots for Safety (F8) and Health/social care (F24)



As shown in Table 10.27 and Figure 10.10, there were very small differences between the three groups on safety, such that community clients reported significantly greater feelings of safety in their daily life than hospital residents; but the differences between the public and hospital residents, and between the public and community clients were small and non-significant. Similarly, community clients reported the highest levels of satisfaction with the care

services available to them, being significantly more satisfied with their health/social care than both hospital residents and the public; but the hospital and public groups demonstrated similar mean scores on this quality of life facet.

Some aspects of these findings may relate to the smaller client numbers and higher staff ratios of the community projects compared with hospital wards. For example, the enhanced feelings of safety of community clients, and the higher satisfaction with care services, may have reflected contextually related closer supervision and support. However, there may have been a residual 'halo' effect (Asch, 1946) still present for community clients in relation to the transition from hospital to community settings, and from predominantly institutional to more individually orientated primary and community care services. The more surprising finding was that the average general public response on health/social care services was similar to that of the hospital residents, and below scale point 4 (satisfied), in a region with arguably one of the most comprehensive ranges of generic and specialist services in the country.

Social Inclusion

The analysis of variance produced no significant difference between the hospital residents, community clients and general public on three of the newly introduced social inclusion items, with all groups demonstrating almost identical mean on items 27 (stigmatisation), 28 (victimisation) and 36 (acceptance).

However, significant differences were found between the participant groups on items 29 (ridicule), 30 (discrimination) and 35 (respect).

The lack of between group discrimination on these items provided strong retrospective support for the inclusive and empirical approach taken to the 17 new themes generated by the focus groups, which were encapsulated as five social justice dimensions and ten related facets (Table 5.18 in Chapter 5).

As shown in Table 10.29, one facet in each of dimensions 1 (social devaluation), 2 (discrimination) and 5 (social acceptance) failed to discriminate between participant types in relation to the current study samples; but one facet in each dimension did produce a significant difference between the groups

Table 10.29: Performance of New Social Inclusion Facets

Focus Group Social Justice Dimensions		Poor Discrimination	Adequate Discrimination
1	Social devaluation	Stigmatisation	Ridicule
2	Discrimination	Victimisation	Discrimination
5	Social acceptance	Acceptance	Respect

The absence of significant differences between the groups in relation to the experience of stigmatisation, victimisation and acceptance may have been an artefact of the high proportion of proxy staff responding on behalf of the two groups of adults with intellectual disabilities (86.9 % for hospital residents and 77.5 % for community clients). In this context the response patterns of some (or even many) staff proxy respondents may have been influenced by both social desirability and cognitive dissonance in relation to these sensitive items.

This may seem somewhat spurious in the light of the differential response patterns on the other three related items. However, the three items that failed to discriminate between the groups might be categorised as capturing aspects of the objective treatment of minority groups, or certain individuals, compared to other people (being called names, being treated unfairly, not being accepted) i.e. the impact of *being* part of a societal 'out group'; while the three items that did produced significant differences between the groups were directed slightly more towards the subjective experience of such targeted individuals (being teased, or being laughed at, because of personal characteristics, being treated differently, or of not being taken seriously) i.e. the effect of *feeling* the difference that defines the 'out group' status.

It may be that staff proxy respondents were more conscious of 'desirable' responses, which did not reflect poorly on their discharge of responsibilities for the care and protection of vulnerable adults with intellectual disabilities, in relation to the treatment orientated facets compared with facets over which they might have perceived themselves to have less control. However, these items could have failed to discriminate between the groups as a result of poor item construction also.

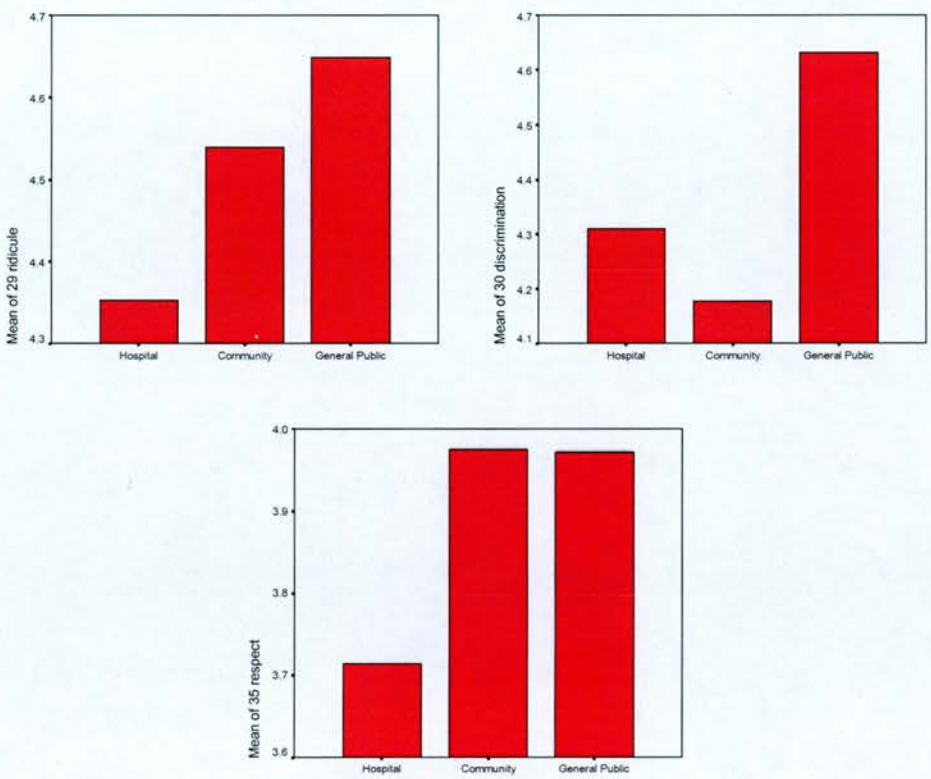
For the three items (ridicule, discrimination and respect) that subsequent post hoc comparisons indicated significant differences between participant groups, the source and direction of these differences varied for each item.

On the first item (ridicule) the post hoc comparisons demonstrated that there was a significant difference between the hospital residents and the public ($p < 0.05$); but no difference was found between the hospital and community groups, or between the community and public groups. On the second item (discrimination) significant differences were found between both groups of adults with intellectual disabilities and the public ($p < 0.05$); but no difference was found between the hospital and community groups. On the third item (respect), significant differences were found between the hospital and community groups, and between the hospital and public groups ($p < 0.05$); but no difference was found between the community and public groups.

As shown in Table 10.27 and Figure 10.11, these findings indicated relatively small differences between the three groups on ridicule, such that the public

reported significantly less experience of ridicule[14] than hospital residents; but the differences between community clients and hospital residents, and between community clients and the public were small and non-significant. The general public reported significantly less experience of discrimination[15] than both the hospital residents and community clients; but hospital residents and community clients were exposed to similar levels of discrimination, despite the presence of the latter group in community settings. Finally, hospital residents experienced significantly lower levels of respect than both community clients and the public; however, in contrast to the findings on ridicule and discrimination, community clients and the public reported similar levels of respect from others.

Figure 10.11: Means Plots for Ridicule (F29), Discrimination (F30) and Respect (F35)



Overall this suggested that community presence, use of local facilities and general participation in local neighbourhoods was not sufficient to enhance the value accorded to adults with intellectual disabilities, as social *ex*clusion in the form of ridicule and discrimination remained similar for both these samples of hospital residents and community clients, compared with their general public counterparts; and although the findings for respect suggested a degree of social

[14] Negatively phrased, therefore scores reversed such that a higher score reflects less frequent ridicule and thus a higher quality of life.

[15] Negatively phrased, therefore scores reversed such that a higher score reflects less frequent discrimination and thus a higher quality of life.

*in*clusion for community clients, this result may have been contaminated by the desire of community staff proxies to believe in the ideology.

Empowerment

The analysis of variance produced significant differences between the hospital residents, community clients and general public on all three newly introduced empowerment items: 31 (enabling), 32 (empowerment) and 33 (autonomy).

Table 10.30: Performance of New Empowerment Facets

Focus Group Social Justice Dimensions	Poor Psychometrics	Adequate Discrimination
3 Social equity	Advocacy	Enabling
4 Empowerment & self determination		Empowerment
		Autonomy

As shown in Table 10.30, one facet (advocacy) in dimension 3 (social equity) of the original five social justice dimensions was identified as having poor psychometric performance (see Chapter 9) and was dropped from further testing in its current format as part of this study; but the remaining facets within the social equity dimension produced a significant difference between the groups; and within dimension 4 (empowerment and self determination) both facets produced significant differences between the groups, suggesting the potential for subdivision of the dimension in terms of these facets.

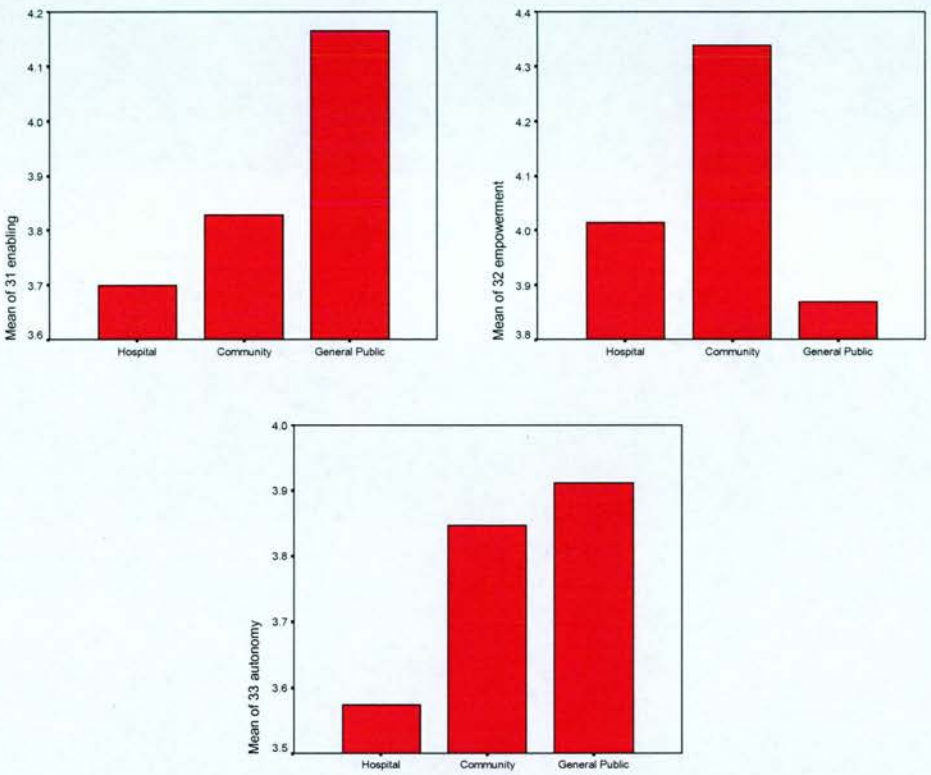
For the three items (enabling, empowerment and autonomy) that subsequent post hoc comparisons indicated significant differences between participant groups, the source and direction of these differences varied for each item.

On the first item (enabling) significant differences were found between both groups of adults with intellectual disabilities and the public ($p < 0.05$); but no difference was found between the hospital and community groups. On the second item (empowerment), there was no significant difference between the hospital and public groups, but a significant difference was found between the community clients and both other groups ($p < 0.05$). On the third item (autonomy), significant differences were found between the hospital and community groups, and between the hospital and public groups ($p < 0.05$); but no difference was found between the community and public groups.

As shown in Table 10.27 and Figure 10.12, these findings indicated that the general public felt significantly more enabled than both the hospital residents and community clients; but the hospital and community groups demonstrated similar lower mean scores on this quality of life facet. The community clients reported the highest levels of empowerment, being significantly more empowered than both hospital residents and the public; but no difference was found between the

degree of empowerment of the hospital and public groups. Finally, hospital residents had significantly less autonomy than both community clients and the public; but community clients and the public reported similar levels of self-determination.

Figure 10.12: Means Plots for Enabling (F31), Empowerment (F32) and Autonomy (F33)



Overall, these results present a conflicting picture, which once again may reflect the impact of proxy respondents. Since the hospital residents and community clients were matched for dependency, and both groups were in multi-occupancy cared-for situations within 24-hour staffed environments, the differential findings for enabling, empowerment and autonomy are confusing, but may be related to facet interpretation; and while the relatively lower level of empowerment reported by members of the public suggested a sense of disenfranchisement on the part of ordinary people in modern life, the higher levels reported for the community group may be a function of socially desirable responding. The trend of responses for both enabling and autonomy were in the expected direction (i.e. $H < C < P$), albeit that some comparisons were non-significant, and clearer results may emerge with larger samples of ID participants with the capacity to describe their own experience directly.

Between Groups Analysis of Domain Configurations

A further series of three level between-groups analyses of variance were carried out to test for differences between the group mean domain scores, with facets aggregated according to the originally hypothesised domains and the empirically suggested alternative structures derived from the exploratory factor analysis and modelled in the confirmatory factor analysis (see Chapter 9), namely:

- The six domain model based on the original four WHOQOL-BREF domains plus the two domain supplementary ID module;
- A five domain alternative CFA model A.1; and
- A six domain alternative CFA model A.2.

The domain scores were calculated according to the guidance set out in the Draft WHOQOL Users Manual (WHO, 1998c), extrapolating for the supplementary ID module and for the alternative domain configurations. The syntax for the computation of the domain scores for all three models is included at A10.2 in Appendix 10.

These domain scores reflected interval data on continuous scales. Prior to conducting the ANOVAs, the domain score variances were inspected for all domain configurations across the three models, and were found to meet the criteria for homogeneity (or similarity) of variance in all cases (as shown in A10.3 in Appendix 10).

BREF Model plus Supplementary ID Module

The statistics obtained from the results of the analysis of variance for the originally hypothesised domain configuration, based on the WHOQOL-BREF model supplemented by an ID module, are summarised in Table 10.31, together with the findings of the subsequent post hoc comparisons, using the Scheffé or Dunnett C method (as appropriate).

Table 10.31: Analysis of WHOQOL Domains: BREF Model plus Supplementary Module

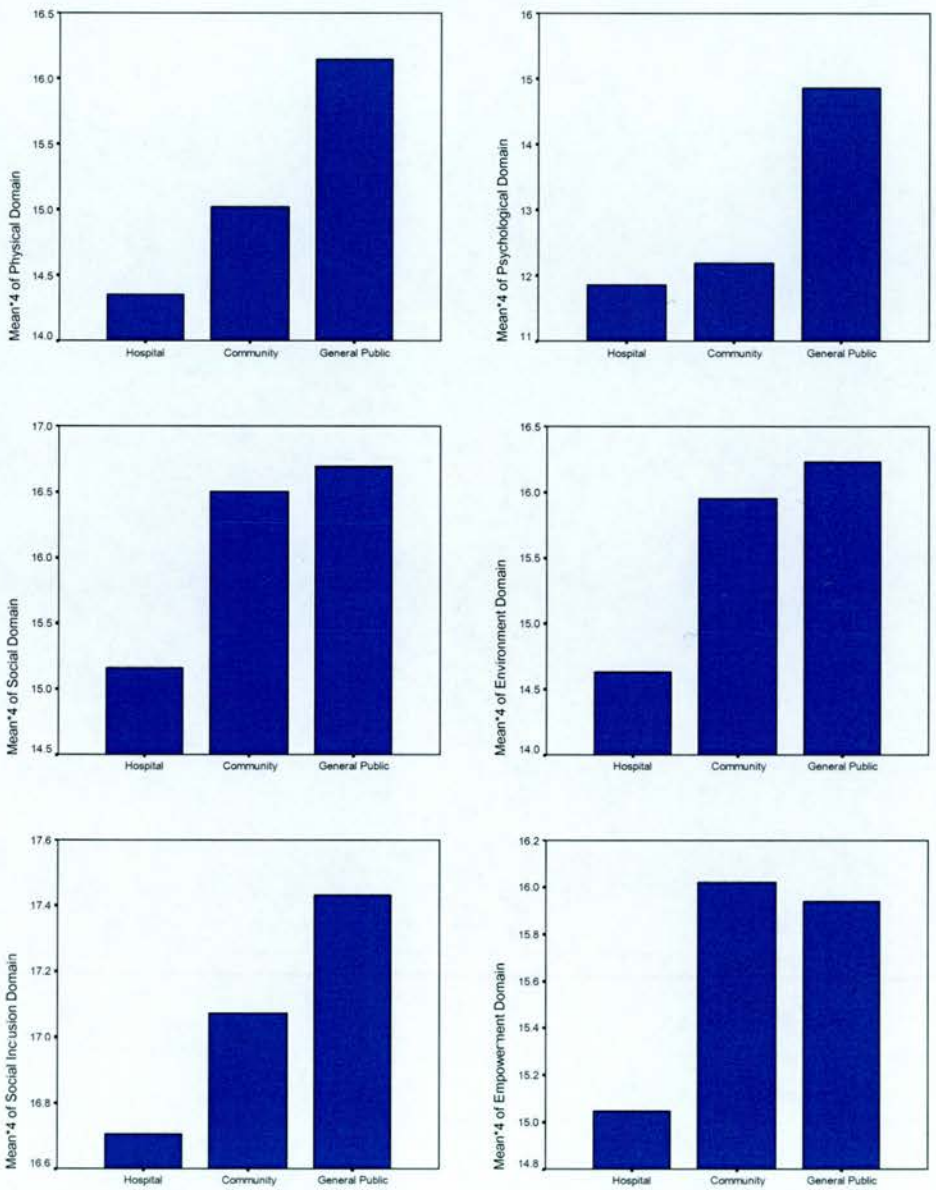
Domain	Mean (*SD*)			ANOVA			Post Hoc
	Hospital ^{H}	Community ^{C}	Public ^{P}	F^{*}	$P <$	Test	$P < 0.05$
Physical	14.36 (± 2.52)	15.02 (± 2.36)	16.15 (± 2.93)	25.249	0.001	DC	H < C < P
Psychological	11.85 (± 2.24)	12.18 (± 2.18)	14.86 (± 2.59)	102.629	0.001	DC	H = C < P
Social	15.16 (± 2.33)	16.50 (± 2.35)	16.69 (± 2.93)	22.474	0.001	DC	H < C = P
Environment	14.63 (± 2.01)	15.96 (± 2.12)	16.23 (± 2.15)	35.135	0.001	S	H < C = P
Social Inclusion	16.70 (± 2.54)	17.07 (± 2.70)	17.43 (± 2.15)	4.514	0.05	DC	H < P, C = H, C = P
Empowerment	15.05 (± 3.41)	16.02 (± 2.77)	15.94 (± 2.44)	7.213	0.005	DC	H < C = P

DC: Dunnett C (variances ≠) S: Scheffé (variances =) F^{*}: varies from $F_{2, 617}$ to $F_{2, 620}$

Significant differences were found between the three participant groups on all six domains, but the source and direction of these differences varied for each domain.

On the physical domain, significant differences were found in relation to every set of group comparisons i.e. hospital v community, community v general public, and hospital v general public ($p < 0.05$). On the social, environment and empowerment domains there were significant differences between the hospital and community groups, and between the hospital and public groups ($p < 0.05$ or better); but no difference was found between the community and public groups.

Figure 10.13: WHOQOL Domain Means Plots: BREF plus Supplementary Module



On the psychological domain, significant differences were found between both groups of adults with intellectual disabilities and the public ($p < 0.05$); but no difference was found between the hospital and community groups. Finally, on the social inclusion domain, there was a significant difference between the hospital residents and the public ($p < 0.05$), but no difference was found between the hospital and community groups, or between the community and public groups.

As shown in Table 10.31 and Figure 10.13, on the physical domain, these findings indicated that hospital residents were less physically able, or had poorer physical capacity, than community clients; and community clients were less physically able, or had poorer physical capacity, than the general public. On the psychological domain, the public reported higher levels of psychological capacity and emotional well-being than both the hospital and community groups; but community clients and hospital residents demonstrated similar levels of psychological capacity and well-being. On the social, environment and empowerment domains, hospital residents experienced impoverished personal and social relationships, lived within poorer environmental circumstances, and had less control of their lives, being generally less empowered, than both community clients and the public; but community clients and the general public enjoyed similar social relationships, benefited from similar environmental circumstances and experienced similar levels of self determination. On the social inclusion domain, the hospital residents experienced less social inclusion and correspondingly more occasions of social exclusion than the general public; but there was little difference between the between community clients and hospital residents, and between community clients and the public on this dimension.

Overall this suggested that the general public remained superior in relation to physical and psychological health; in terms of environmental circumstances, social relationships and empowerment, the impact of resettlement had enhanced the lives of community clients compared with that of their hospital counterparts, approaching a level similar to that of the general population and reflecting a considerable degree of 'normalisation'; however, in terms of social inclusion (and in the context of a high proportion of proxy respondents in the two groups of ID adults) the picture was more mixed and ambiguous.

CFA 5 Domain Model A.1

The statistics obtained from the results of the analysis of variance for the alternative five domain configuration, based on the most robust of the factor solutions derived for the 35 constituent facets, are summarised in Table 10.31, together with the findings of the subsequent post hoc comparisons, using the Scheffé or Dunnett C method (as appropriate).

Table 10.32: Analysis of WHOQOL Domains: CFA 5 Domain Model A.1

Domain	Mean (*SD*)			ANOVA			Post Hoc
	Hospital ^{H}	Community ^{C}	Public ^{P}	F^*	$P <$	Test	$P < 0.05$
Social & Emotional Care/Support	15.39 (± 1.81)	16.64 (± 1.88)	16.14 (± 2.22)	21.107	0.001	DC	H < P < C
Functional Ability	12.52 (± 2.53)	13.16 (± 2.37)	15.81 (± 2.47)	104.821	0.001	S	H < C < P
Social Inclusion	16.70 (± 2.54)	17.07 (± 2.70)	17.43 (± 2.15)	4.514	0.05	DC	H < P, C = H, C = P
Empowerment & Participation	14.06 (± 2.95)	14.98 (± 2.81)	15.93 (± 2.37)	24.633	0.001	DC	H < C < P
Physical & Mental Health	13.16 (± 2.98)	13.45 (± 2.73)	15.39 (± 3.14)	34.784	0.001	S	H = C < P

DC: Dunnett C (variances ≠) S: Scheffé (variances =) F^*: varies from $F_{2, 619}$ to $F_{2, 621}$

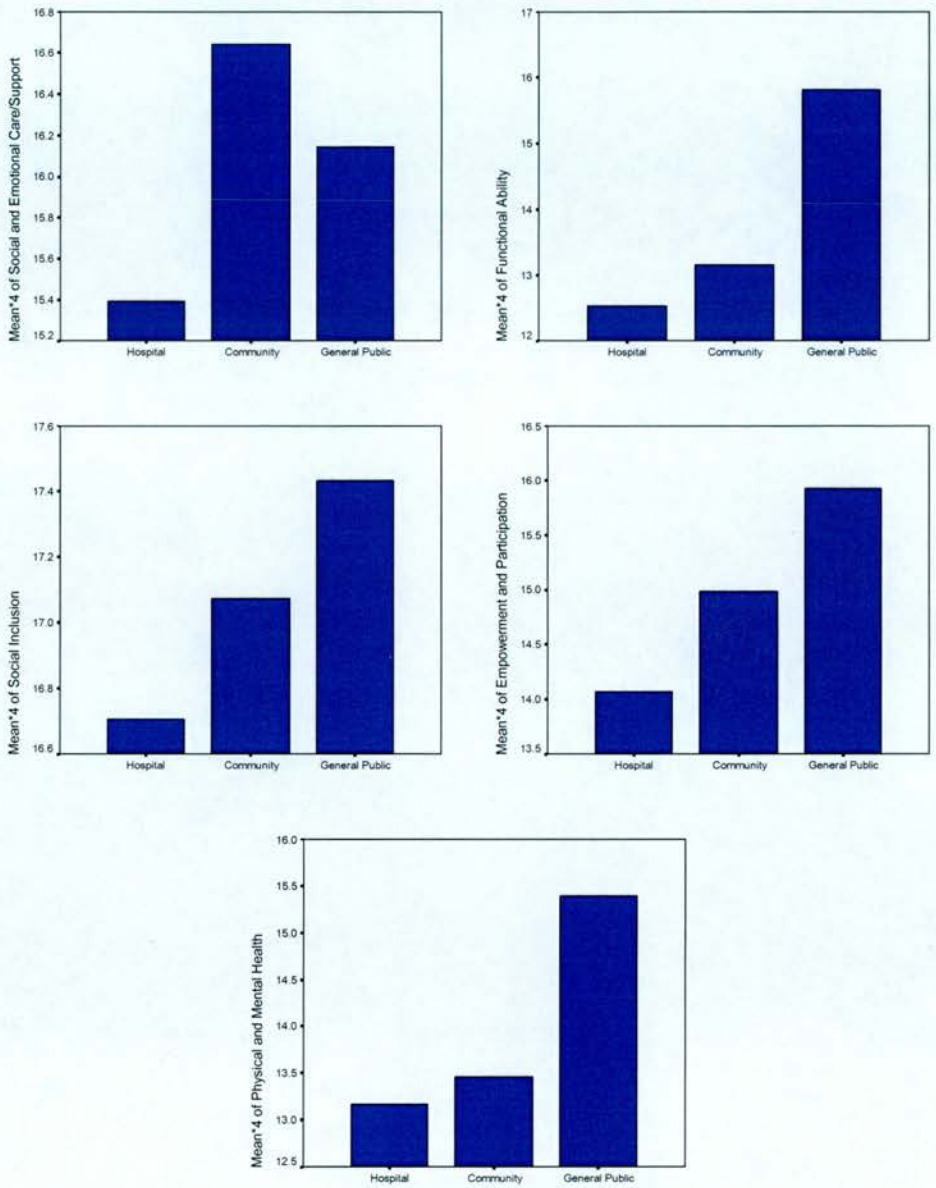
Significant differences were found between the three participant groups on all five domains, but once again, the source and direction of these differences varied across domains.

On three domains, social and emotional care/support, functional ability, and empowerment and participation, the post hoc comparisons revealed significant differences in relation to every set of group comparisons i.e. hospital v community, community v general public, and hospital v general public ($p < 0.05$ or better). On the physical and mental health domain, significant differences were found between both groups of adults with intellectual disabilities and the public ($p < 0.05$); but no difference was found between the hospital and community groups. Finally, on the social inclusion domain, there was a significant difference between the hospital residents and the public ($p < 0.05$); but no difference was found between the hospital and community groups, or between the community and public groups.

As shown in Table 10.31 and Figure 10.14, these findings indicated that hospital residents had poorer functional ability, experienced less empowerment and participated less, than community clients; and in turn, community clients had lower functional ability, were constrained by lower levels of empowerment and had fewer opportunities for participation than the general public. Furthermore, the public enjoyed superior physical and mental health compared with both hospital residents and community clients, the physical and psychological health of whom remained similarly poorer. However community clients demonstrated higher levels of social and emotional care/support than both hospital residents and the public; although the public reported experiencing more social and emotional support than hospital residents.

(As the social inclusion domain remained robust and consistent, and comprised exactly the same set of six facets all three models, the picture that emerged on this domain from the CFA 5 domain model A.1 was exactly as described for the BREF model with the supplementary ID module).

Figure 10.14: WHOQOL Domain Means Plots: CFA 5 Domain Model A.1



Overall this domain configuration yielded a consistent pattern of relative superiority for the general public in relation to physical and mental health, functional ability, and empowerment and participation. The superiority of the community clients on social and emotional care/support, is consistent with the findings for the social support facet, and as noted in this context, may be explained in terms of the nature of the community oriented projects and the service principles underpinning the commitment of staff to a client centred regime.

CFA 6 Domain Model A.2

The analysis of variance for the alternative six-domain structure, based on the less robust of the factor solutions derived for the 35 constituent facets, was carried out also. Significant differences were found between the three participant groups on all six domains, and post hoc tests were conducted to identify the source and direction of these significant differences. However, as three of the domains (and hence the domain scores) were identical to the five-domain model discussed above, the results are not discussed in detail here. A summary of the six-domain model statistics, together with the findings of the subsequent Scheffé or Dunnett C post hoc comparisons, are summarised in Table A10.4; and the associated domain means plots are presented at A10.5, both in Appendix 10.

Response Mode Analysis

As described for the LEC, of the combined group of adults with intellectual disabilities, 74 participants (18%) responded directly to the WHOQOL-ID and staff proxies responded on behalf of the remaining 343 participants (82%). A series of independent samples *t*-tests were used to analyse the mean domain scores for these two subgroups to test for differences associated with response mode. These analyses were conducted for both of the main domain configurations: the BREF plus supplementary ID module (model B+2) and the CFA 5 domain (model A.1).

Table 10.33: Variance of Domain Scores by Response Mode for Model B+2

Subgroup	*N*	%	Physical	Psychological	Social	Environment	Social Inclusion	Empowerment
Direct	74	17.7	5.80	6.92	8.61	6.12	9.35	10.15
Proxy	343	82.3	5.87	3.49	5.08	4.16	6.34	9.81

Table 10.34: Variance of Domain Scores by Response Mode for Model A.1

Subgroup	*N*	%	Social & Emotional Care/Support	Functional Ability	Social Inclusion	Empowerment & Participation	Physical & Mental Health
Direct	74	17.7	5.72	6.61	9.35	8.41	8.41
Proxy	343	82.3	3.25	4.89	6.34	8.10	8.15

As shown in Tables 10.33 and 10.34, the numbers in the direct and proxy subgroups were unequal (although reasonably large), but the domain score variances were sufficiently similar for the key assumption of homogeneity of

variance to be met for both models (in all cases the larger variance being considerably less than three times the smaller variance) and therefore it was legitimate to use a *t*-test to compare the means of the two groups, as the test remains sufficiently robust in these circumstances (Clark-Carter, 1997).

The statistics obtained from the results of the *t*-tests are summarised in Table 10.35. Significant differences were found between the direct and proxy subgroups in relation to four out of six domains for model B+2, and three out of five domains for model A.1.

Table 10.35: Analysis of WHOQOL Domain Scores by Response Mode

Domains	Mean (*SD*)		*t*- test (2- tailed)			
	Direct (*N* = 74)	Proxy (*N* = 343)	*t*	*P* <	*df*	Variances
	BREF + Supplementary ID Module Model B+2					
Physical	15.68 (± 2.41)	14.46 (± 2.42	3.932	0.001	415	=
Psychological	13.96 (± 2.63)	11.59 (± 1.87)	7.316	0.001	88.042	≠
Social	16.85 (± 2.93)	15.60 (± 2.25)	3.454	0.01	92.425	≠
Environment	16.21 (± 2.47)	15.08 (± 2.04)	4.164	0.001	414	=
Social Inclusion	16.48 (± 3.06)	16.97 (± 2.52)	1.467	NS	415	=
Empowerment	16.05 (± 3.19)	15.41 (± 3.13)	1.602	NS	415	=
	CFA 5 Domain Model A.1					
Social & Emotional Care/Support	16.68 (± 2.30)	15.86 (± 1.80)	2.809	0.01	91.680	≠
Functional Ability	14.91 (± 2.57)	12.39 (± 2.21)	8.627	0.001	415	=
Social Inclusion	16.48 (± 3.06)	16.97 (± 2.52)	1.467	NS	415	=
Empowerment & Participation	15.77 (± 2.90)	14.24 (± 2.85)	4.184	0.001	415	=
Physical & Mental Health	13.44 (± 2.90)	13.28 9± 2.86)	0.453	NS	415	=

As shown in Table 10.35, for model B+2, significant differences were found between the mean domain scores for the direct and proxy subgroups for the 'base' physical, psychological, social and environment domains (*t* values between 3.454 and 7.316, significant at $p < 0.01$ or better). However, no significant differences were found between the subgroups for the two 'new' social inclusion and empowerment domains.

For model A.1, significant differences were found between the mean domain scores for the direct and proxy subgroups for the social and emotional care/support, functional ability, and empowerment and participation domains (*t* values between 2.809 and 8.627, all significant at $p < 0.001$). However, no significant differences were found between the subgroups for the social inclusion (same facet configuration as for B+2) and physical and mental health domains. The direction of all the significant differences on the domain scores in respect of both models was uniform, with the mean score of the proxy subgroup being significantly lower than that of the direct subgroup.

The findings for model B+2 suggested that the adults with intellectual disabilities who responded directly to the WHOQOL-ID had superior physical health, psychological well-being, social relationships and environmental circumstances compared with those for whom proxy responses were obtained; and similarly, for model A.1, direct respondents had superior social and emotional care/support, functional ability, and empowerment and participation compared with individuals unable to respond directly. Thus, on these dimensions, direct respondents appeared to have a superior quality of life compared to indirect respondents, a finding consistent with the outcomes for the LEC.

In contrast, the direct and proxy subgroups appeared to have similar life quality in relation to social inclusion and to the facets of empowerment when not associated with those of participation in model B+2; and in respect of social inclusion and physical and mental health in model A.1.

Following the finding of a significant negative relationship between response mode and level of dependency (discussed in relation to the LEC results, see Tables 10.22 and 10.23), the pattern of WHOQOL-ID domain correlations (Pearson's *r*) and the relationship between the domain scores and the nine DDRS categories[16] (Spearman's rho) were inspected for both model configurations.

Table 10.36: Correlations of Domain and Dependency Measures for Model B+2

WHOQOL-ID & Dependency	Corr.	*N*	Physical	Psychological	Social	Environment	Social Inclusion	Empowerment
Physical	*r*	417	1.0					
Psychological	*r*	416	0.5**	1.0				
Social	*r*	417	0.3**	0.4**	1.0			
Environment	*r*	416	0.4**	0.5**	0.5**	1.0		
Social Inclusion	*r*	417	0.1*	0.1*	0.2**	0.2**	1.0	
Empowerment	*r*	417	0.3**	0.3**	0.3**	0.4**	0.3**	1.0
DDRS Categories	rho	412	-0.2**	-0.3**	-0.1	-0.2**	0.0	-0.1**

Missing cases: DDRS = 5 (community) Psychological & Environment Domains = 1 each (community)
** Significant at 0.01 level (2-tailed) * Significant at 0.05 level (2-tailed)

As shown in Tables 10.36 and 10.37, a range of low to moderate positive inter-domain correlations were found for both models, B+2 and A.1, consistent with the use of an orthogonal approach to determining factor solutions for the WHOQOL (based on the original WHOQOL methodology, WHOQOL Group, 1998b). However, the pattern of correlations between the dependency and the domain scores tended to show weaker associations.

[16] The main dependency measure (see Chapters 4 and 8), on which DDRS data were available for all ID clients.

Table 10.37: Correlations of Domain Scores and Dependency Measures for Model A.1

WHOQOL-ID & Dependency	Corr	*N*	Social & Emotional	Functional Ability	Social Inclusion	Empower. & Participation	Physical & Mental
Social & Emotional Care/Supp	*r*	417	1.0				
Functional Ability	*r*	417	0.5**	1.0			
Social Inclusion	*r*	417	0.3**	0.0	1.0		
Empowerment & Participation	*r*	417	0.4**	0.4**	0.2**	1.0	
Physical & Mental Health	*r*	417	0.3**	0.3**	0.2**	0.1**	1.0
DDRS Categories	rho	412	-0.1**	-0.3**	0.0	-0.2**	-0.1**

Missing cases: DDRS = 5 (community) ** Significant at 0.01 level (2-tailed)

For model B+2, a non-significant negative correlation was found between the social domain and dependency; no relationship was found between social inclusion and dependency; but low to moderate significant negative correlations were found between dependency and the other four domains, physical, psychological, environment and empowerment (rho values ranging from 0.1 to 0.3, $p < 0.01$).

Similarly for model A.1, no relationship was found between the social inclusion domain and dependency; but low to moderate significant negative correlations were found between dependency and the remaining four domains, social and emotional care/support, functional ability, empowerment and participation, and physical and mental health (rho values ranging from 0.1 to 0.3, $p < 0.01$).

Despite the more subjective nature of the WHOQOL-ID (compared with the objective LEC), and with due caution given the relatively low numbers of ID clients in the direct response subgroup, these results suggested once again that level of dependency might not account fully for the differential quality of life outcomes on those domains for which significant differences were found for response mode. Therefore, partial correlations between the domain scores and dependency were carried out to control for the effect of direct or proxy response mode.

Table 10.38: Partial Correlations of Domain Scores and Dependency for Model B+2 (controlling for Response Mode)

Dependency	*df*	Physical	Psychological	Social	Environment	Social Inclusion	Empowerment
DDRS Categories[17]	407	-0.09	-0.15**	0.02	-0.15**	0.04	-0.11*

Missing cases: DDRS = 5 (community) Psychological & Environment Domains = 1 each (community)
** Significant at 0.01 level (2-tailed) * Significant at 0.05 level (2-tailed)

[17] Assumed to be a continuous scale for the purpose of conducting the partial correlation.

As shown in Table 10.38, for model B+2, extremely low non-significant positive correlations were found between dependency and both the social and social inclusion domains; an extremely low non-significant negative correlation was found between dependency and the physical domain; and only very low significant negative correlations were found between dependency and the psychological, environment and empowerment domains ($r < -0.2$).

Table 10.39: Partial Correlations of Domain Scores and Dependency for Model A.1 (controlling for Response Mode)

Dependency	*df*	Social & Emotional Care/ Support	Functional Ability	Social Inclusion	Empowerment & Participation	Physical & Mental Health
DDRS Categories[18]	409	-0.04	-0.13**	0.04	-0.15**	-0.12*

Missing cases: DDRS = 5 (community) ** Significant at 0.01 level (2-tailed) * Significant at 0.05 level (2-tailed)

Similarly, as shown in Table 10.39, for model A.1, an extremely low non-significant positive correlation was found between dependency and the social inclusion domain; an extremely low non-significant negative correlation was found between dependency and the social and emotional care/support domain; and only very low significant negative correlations were found between dependency and the functional ability, empowerment and participation, and physical and mental health domains ($r < -0.2$).

These findings tended to confirm that the level of dependency of the adults with intellectual disabilities had a relatively weak association with the WHOQOL-ID domain scores on both models. This was consistent with the findings for the LEC subsection and total scores, and provided additional support for the suggestion that the significant differences found between the direct and proxy subgroups might be related to the perceptions of proxy staff about the individuals' subjective experience of life. However, for the WHOQOL-ID, significant differences between subgroups by response mode were found only on four domains in model B+2 and three domains in model A.1. This suggested that the effect of proxy staff perceptions (if these partially accounted for domain score differences) either had more impact on certain quality of life dimensions, or were operating selectively.

Table 10.40 shows the direct and proxy subgroup mean scores on the individual facets for the domains on which no significant response mode difference was found across the two models. There were significant differences between the subgroups on two facets only, stigmatisation in the social inclusion domain and enabling in the empowerment domain. On all other facets the direct and proxy subgroup scores were similar.

[18] Assumed to be a continuous scale for the purpose of conducting the partial correlation.

Table 10.40: Direct and Proxy Scores for Non-Significant Domains by Response Mode

Domain / Facet	Mean (*SD*)		*t*- test (2- tailed)			
	Direct (*N* = 74)	Proxy (*N* = 343)	*t*	*P* <	*df*	Variances
Social Inclusion Domain - Models B+2 and A.1						
Stigmatisation ®	4.2 (± 1.1)	4.6 (± 0.8)	2.764	0.01	88.980	≠
Victimisation ®	4.1 (± 1.1)	4.0 (± 1.0)	0.684	NS	415	=
Ridicule ®	4.2 (± 1.1)	4.5 (± 0.8)	1.901	NS	89.721	≠
Discrimination ®	4.2 (± 1.1)	4.3 (± 1.0)	0.147	NS	414	=
Respect	3.7 (± 1.3)	3.9 (± 0.9)	1.103	NS	87.315	≠
Acceptance	4.3 (± 1.0)	4.3 (± 0.8)	0.109	NS	415	=
Empowerment Domain - Model B+2						
Enabling	4.1 (± 1.0)	3.7 (± 1.1)	3.275	0.01	415	=
Empowerment	4.3 (± 1.0)	4.2 (± 0.9)	0.885	NS	415	=
Autonomy	3.7 (± 1.0)	3.7 (± 0.9)	0.622	NS	415	=
Physical & Mental Health Domain - Model A.1						
Pain ®	4.0 (± 1.26)	4.1 (± 1.10)	0.443	NS	415	=
Medication ®	2.8 (± 1.15)	2.8 (± 1.19)	0.400	NS	415	=
Negative Feelings ®	3.3 (± 1.01)	3.1 (± 0.74)	1.038	NS	90.819	≠

® Recoded negatively phrased items

It is noteworthy that approximately half of the facets in these three domains (seven out of twelve) were negatively phrased, such that lower raw scores were indicative of higher quality of life. (All recoded prior to domain score computation, such that higher scores represented higher quality of life, consistent with the scoring of other facets.) It is possible that respondents found this negative format confusing. However, staff proxy respondents were provided with a response scale card (see A8.27 in Appendix 8) and clients were provided with pictorially augmented versions of the response scales (see A8.19 - A8.26 in Appendix 8) to assist and support selection from the response options. These response prompts included both the numerical score and the associated scale descriptor (and for clients, the appropriate 'smiley face' visual representation) and thus it was unlikely that the results could be accounted for by simple misunderstandings.

A more plausible explanation of the response mode similarity may lie in the thematic content of these domains and the potential for staff proxy respondents to have been influenced both by social desirability and by cognitive dissonance. As noted earlier, staff may have been concerned to provide responses that did not reflect poorly on their discharge of responsibilities for the care and protection of vulnerable adults with intellectual disabilities, particularly in respect of areas under their direct charge, e.g. physical and mental health; within their span of control e.g. empowerment; or for which there exited a clear service philosophy, e.g. social inclusion.

WHOQOL Version Analysis

Two subgroups of the general public, matched on the key variables of age, gender and residential locality (see Chapter 8) were presented with two different versions of the WHOQOL measure: the adapted WHOQOL-ID and the original WHOQOL-BREF supplemented by the ID module.

A series of independent samples *t*-tests were used to analyse the mean domain scores for these two subgroups to test for any differences associated with WHOQOL version. These analyses were conducted for both the main domain configurations: model B+2 and model A.1.

Table 10.41: Variance of Domain Scores by WHOQOL Version for Model B+2

Version	*N*	%	Physical	Psychological	Social	Environment	Social Inclusion	Empowerment
ID	103	50.0	8.66	7.22	7.91	5.88	3.72	5.04
BREF	105	50.0	8.54	5.57	8.78	3.46	5.50	6.76

Table 10.42: Variance of Domain Scores by WHOQOL Version for Model A.1

Version	*N*	%	Social & Emotional Care/Support	Functional Ability	Social Inclusion	Empowerment & Participation	Physical & Mental Health
ID	103	50.0	5.75	7.27	3.72	5.67	8.28
BREF	105	50.0	4.08	4.77	5.50	5.54	10.98

As shown in Tables 10.41 and 10.42, the numbers in the two subgroups were approximately equal and the domain score variances were sufficiently similar for the key assumption of homogeneity of variance to be met for both models and therefore it was legitimate to use a *t*-test to compare the means of the two groups (Clark-Carter, 1997).

The statistics obtained from the results of the *t*-tests are summarised in Table 10.43. Significant differences were found between the two public groups on the two versions of the instrument in relation to two out of six domains for model B+2, and one out of five domains for model A.1.

For model B+2, no significant differences were found between the mean scores for the ID and BREF subgroups on the physical, environment, social inclusion or empowerment domains; but significant differences were found on both the psychological domain ($t = 3.402$, $df = 203$, $p < 0.01$, two-tailed, variances equal) and social domain ($t = 2.563$, $df = 203$, $p < 0.05$, two-tailed, variances equal).

Table 10.43: Analysis of WHOQOL Domain Scores for Public Group by Version

Domains	Mean (*SD*)		*t*- test (2- tailed)			
	ID (*N* = 103)	BREF (*N* = 105)	*t*	*P* <	*df*	Variances
	BREF + Supplementary ID Module Model B+2					
Physical	16.19 (± 2.94)	16.11 (± 2.92)	0.188	NS	204	=
Psychological	14.25 (± 2.69)	15.46 (± 2.36)	3.402	0.01	203	=
Social	17.21(± 2.81)	16.18 (± 2.96)	2.563	0.05	203	=
Environment	16.17 (± 2.43)	16.29 (± 1.86)	0.403	NS	189.333	≠
Social Inclusion	17.47 (± 1.93)	17.40 (± 2.35)	0.230	NS	203	=
Empowerment	16.22 (± 2.25)	15.67 (± 2.60)	1.621	NS	204	=
	CFA 5 Domain Model A.1					
Social & Emotional Care/Support	16.31(± 2.40)	15.98 (± 2.02)	1.061	NS	198.650	≠
Functional Ability	15.48 (± 2.70)	16.15 (± 2.18)	1.957	NS	204	=
Social Inclusion	17.47 (± 1.93)	17.40 (± 2.35)	0.230	NS	203	=
Empowerment & Participation	16.12 (± 2.38)	15.74 (± 2.35)	1.173	NS	204	=
Physical & Mental Health	14.89 (± 2.88)	15.88 (± 3.31)	2.287	0.05	204	=

For model A.1, no significant differences were found between the mean scores for the ID and BREF subgroups on the social and emotional care/support, functional ability, social inclusion or empowerment and participation domains; but a significant difference was found on the physical and mental health domain ($t = 2.287$, $df = 204$, $p < 0.05$, two-tailed, variances equal).

The direction of the significant differences found was not uniform. For model B+2, the BREF version subgroup was superior on the psychological domain, but the ID version subgroup was superior on the social domain; and for model A.1, the BREF version subgroup was superior on the physical and mental health domain.

Although the two public subgroups were matched on the three designated key variables within the study, their characteristics may have differed on other variables, and that may have accounted for the differences found. However, since significant differences were found on only three domains across the eleven included in the two models, and since the direction of difference varied, it was likely that some subgroup variation may have been attributable to the impact of instrument adaptation.

The ID and BREF subgroup mean scores and summarised *t*-test statistics for the individual items within domains on which significant differences were found for the two versions of the instrument are presented in Table 10.44. As shown, there were no significant differences between the mean scores of the public subgroups on five items. This suggested that these items performed satisfactorily in terms of equivalence across the instrument versions.

Table 10.44: Public Subgroup Scores for Significant Domains by WHOQOL Version

Domain / Facet	Mean (*SD*)		*t*- test (2- tailed)			
	ID (*N* = 103)	BREF (*N* = 105)	*t*	*P* <	*df*	Variances
Psychological Domain - Models B+2						
Positive feelings	4.2 (± 0.9)	4.0 (± 0.7)	1.376	NS	193.754	≠
Spirituality	2.7 (± 1.5)	3.8 (± 0.8)	6.612	0.001	149.120	≠
Thinking	4.1(± 0.9)	3.8 (± 0.8)	2.069	0.05	203	=
Body image	3.2 (± 1.1)	4.1 (± 0.9)	6.381	0.001	202.086	≠
Self esteem	4.0 (± 0.9)	3.9 (± 0.9)	1.162	NS	204	=
Negative feelings	3.3 (± 0.7)	3.7 (± 0.9)	3.665	0.001	185.099	≠
Social Domain - Model B+2						
Personal relationships	4.3 (± 0.8)	4.2 (± 0.9)	1.123	NS	192	=
Sexual activity/Special relationship	4.4 (± 0.9)	3.7 (± 1.1)	4.662	0.001	194	=
Social support	4.2 (± 0.9)	4.1 (± 0.8)	0.677	NS	205	=
Physical & Mental Health Domain - Model A.1						
Pain	4.1(± 0.9)	4.2 (± 1.0)	0.345	NS	200.758	≠
Medication	3.8 (± 1.3)	4.1 (± 1.1)	1.837	NS	193.186	≠
Negative Feelings	3.3 (± 0.7)	3.7 (± 0.9)	3.665	0.001	185.099	≠

Significant differences were found between the mean scores of the public subgroups on six items within the psychological and social dimensions of the WHOQOL BREF and WHOQOL-ID. As shown in Table 10.44, the direction of the differences varied across these items, with the significantly higher mean scores linked with the BREF subgroup on three items, and with the ID subgroup on two items.

The absence of a consistent pattern of version related differences tended to suggest that aspects of the instrument adaptation (specifically item revision, response scale descriptor revision and emphatic shift) might account for the differences found between the subgroups. In this connection it was notable that no subgroup differences were found for any of the 10 additional items that formed part of the ID supplementary module, which was presented to both public subgroups with identical item wording and response scale format.

Item Revision

The details of the original and revised versions of the items on which significant differences were found between the two public subgroups are presented in Table 10.45. As shown, although there were some small differences in item wording (or use of prompts), reasonable thematic equivalence and item semantic equivalence seemed to have been maintained for items 7 (thinking), 11(body image) and 26 (negative feelings).

Table 10.45: Comparison of Original and Adapted WHOQOL Items

Item	Facet	WHOQOL-BREF Item	WHOQOL-ID Revised Item
6	Spirituality	To what extent do you feel your life to be meaningful?	Is god (or are religious things) important in your life? *For example, do you go to Church?*
7	Thinking	How well are you able to concentrate?	How well are you able to concentrate? *Prompt: How easy or difficult is it to think clearly or pay attention to things?*
11	Body image	Are you able to accept your bodily appearance?	Are you happy or unhappy with the way your body looks?
26	Negative feelings	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	How often do you feel unhappy, sad or worried?
21	Sexual activity / Special relationship	How satisfied are you with your sex life?	Do you have close or special relationship with someone? • If yes, how happy or unhappy are you with that relationship? • If no, how happy or unhappy are you about this?

As a result of the requirements of adaptation and revision for an intellectual disabilities population, although broad thematic equivalence may have been maintained, the wording of items 6 (spirituality) and 21 (BREF: sexual activity, ID: special relationship) differed considerably and thus semantic equivalence may have been lost.

(i) Spirituality

On this item the ID version of the instrument employed a concrete example of spirituality to exemplify the conceptual substance of the facet in a way that would be intelligible to adults with intellectual disabilities. However, when used with the general public it may have prompted a different response set.

As shown in Table 10.46 in responding to the '*life meaningful?*' item wording, only 5% of the BREF general public subgroup responded at the lower scale points 1/2, compared with 50% of the ID public subgroup responding to the '*god or religion important?*' item wording; and similarly 80% of the BREF public subgroup responded at the upper scale points 4/5, compared with only 32% of the ID public subgroup. (As the scale point descriptors were similar for both item versions, Table 10.46 uses the original BREF version for the purpose of comparison.)

Table 10.46: Public Response Frequency Distribution for Spirituality

WHOQOL Version	Not at all		A little		A moderate amount		Very much		An extreme amount	
	1		2		3		4		5	
	N	%	*N*	%	*N*	%	*N*	%	*N*	%
BREF (*N* = 105)	1	1.0	4	3.9	24	23.3	60	58.3	14	13.6
ID (*N* = 103)	32	31.4	19	18.6	18	17.6	14	13.7	19	18.6

Missing cases: BREF subgroup = 2 ID subgroup = 1

These findings suggested that the two public groups may have been responding to items that were perceived as fundamentally different, in the light of which, this item may require to be reconsidered (and alternative wordings piloted) for future versions of the WHOQOL-ID.

(ii) Sexual activity / Special relationship

On this item the ID version of the instrument sought to maximise applicability (and minimise sensitivities) for adults within the full range of intellectual disabilities by widening the concept of the original sexual activity item to include 'close or special' relationships. In the pilot version of the WHOQOL-ID the word 'sexual' was retained parenthetically in the item, and the word 'physical' was included also, but as a result of the field trial, the item was amended and these words were removed (see Chapter 6). With hindsight, it may have been a mistake to make such changes as a result of the response to, and feedback from, one relatively small pilot study, as the thematic shift may have been accompanied by loss of semantic equivalence.

Table 10.47: Public Response Frequency Distribution for Sexuality/Special Relationship

WHOQOL Version	Very dissatisfied		Dissatisfied		Neither satisfied nor dissatisfied		Satisfied		Very satisfied	
	1		2		3		4		5	
	N	%	*N*	%	*N*	%	*N*	%	*N*	%
BREF (*N* = 105)	4	4.2	8	8.4	20	21.1	41	43.2	22	23.2
ID (*N* = 103)	3	3.0	2	2.0	5	5.0	35	34.7	56	55.4

Missing cases: BREF subgroup = 10 ID subgroup = 2

As shown in Table 10.47, response frequency differences were less marked on this item, but responding to the *'sexual activity'* item wording, only 23% of the BREF general public subgroup responded at upper scale point 5, compared with 55% of the ID public subgroup responding to the *'special relationship'* item wording (BREF scale point descriptors used for comparison).

Response Scale Revision

The details of the response scales associated with the constituent items on which significant differences were found between the two public subgroups are presented in Table 10.48. As shown, although there were some minor differences in scale anchor or intermediate scale point descriptors, reasonable descriptor equivalence seemed to have been maintained for items 6 (spirituality), 21 (sexual activity / special relationship) and 26 (negative feelings).

Table 10.48: Comparison of Response Scales for Original and Adapted WHOQOL Items

Item	Facet	Version	Anchor 1	2	Intermediate Scale Points 3	4	Anchor 5
6	Spirituality	BREF	Not at all	A little	A moderate amount	Very much	An extreme amount
	Spirituality	ID	Not at all	A little bit	A medium amount	Quite a lot	A great deal (an extremely big amount)
7	Thinking	BREF	Not at all	A little	A moderate amount	Very much	Extremely
	Thinking	ID	Very difficult	A bit difficult	About in the middle	Quite easy	Very easy
11	Body image	BREF	Not at all	A little	Moderately	Mostly	Completely
	Body image	ID	Very unhappy	A bit unhappy	About in the middle	Quite happy	Very happy
21	Sexual activity	BREF	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
	Special Relationship	ID	Very unhappy	A bit unhappy	About in the middle	Quite happy	Very happy
26	Negative feelings	BREF	Never	Seldom	Quite often	Often*	Always
	Negative feelings	ID	Never	Not very often	Sometimes	Often*	Always

* Modified for all groups in main study (see Chapter 8)

As a result of the adaptation for an intellectual disabilities population, the response format for item 7 (thinking) and item 11 (body image) differed considerably between the two versions of the instrument.

(i) Thinking

On this item, the wording remained identical, but a replacement response scale was employed rather than an adapted version of the original scale, and an associated prompt that reflected the new response scale was incorporated also. Although the adults with intellectual disabilities readily understood the *difficult-easy* response continuum, confusion and ambiguity may have been introduced, confounding the thematic equivalence of the item: for example it is possible both to think or concentrate extremely well (BREF scale point 5), and also find thinking and concentration very difficult (ID scale point 1). Therefore, this response scale may benefit from further revision and pilot trials in alternative formats prior to further use of the WHOQOL-ID.

(ii) Body image

On this item the wording was subject to minor revisions to overcome conceptual difficulties with the original terminology 'accept your bodily appearance'. The associated response scale was then amended to be consistent with the revised item encapsulated as being 'happy or unhappy' with body image. However, this may have confounded the thematic equivalence of the item: for example it is possible both to be a bit unhappy with bodily appearance (ID scale point 2) and still mostly accept body image (BREF scale point 4). Therefore this response scale may benefit from further revision for future versions of the WHOQOL-ID.

Emphatic Shift

In relation to item 26 (negative feelings), facet thematic equivalence and item semantic equivalence seemed to have been maintained; and a very similar response format was employed on both versions of the instrument. The differences found between the two public subgroups may have reflected genuine variation in emotional or psychological state; however, it is possible that an emphatic shift, or a change in weight of the item, contributed to the differences found. On the BREF version of the instrument, the use of the relatively formal or technical words 'despair, anxiety and depression' may have focussed attention on a more serious set of negative feelings than the words 'unhappy, sad or worried' used in the WHOQOL-ID i.e. the revised ID wording may have shifted the item emphasis towards the less serious end of the negative feelings spectrum.

As shown in Table 10.44, the public responding to the BREF version of the item had a higher mean score, and thus a higher quality of life, than their counterparts responding to the ID version. However, this was one of the negatively phrased items, with scores recoded prior to the computation of domain scores.

Table 10.49: Public Response Frequency (Raw Score) Distribution for Negative Feelings

WHOQOL Version	Never		Not very often		Sometimes		Often		Always	
	1		2		3		4		5	
	N	%	*N*	%	*N*	%	*N*	%	*N*	%
BREF (*N* = 105)	11	10.8	63	61.8	14	13.7	11	10.8	3	2.9
ID (*N* = 103)	1	1.0	36	35.3	53	52.0	12	11.8	0	0

Missing cases: BREF subgroup = 3 ID subgroup = 1

As shown in Table 10.49, the raw score distribution along the response scale indicated that 73% of the public reported experience of negative feelings at *lower* scale points 1/2 for the BREF item, compared with the 36% for the ID item, consistent with possible differential perceptions of item weight.

10.3 Relationship Between Objective and Subjective Quality of Life Measures

The two quality of life measures used in the study drew on different aspects of the conditions and experience of life of the participants. A series of correlations were performed to determine the degree of association between the LEC total score and the WHOQOL-BREF or WHOQOL-ID total score in relation to the two WHOQOL models B+2 and A.1.

The LEC total score was obtained by summing the scores of all items within the five subsections: home, leisure, relationships, freedom and opportunities. The WHOQOL total score was obtained by summing the six domain scores (model B+2) or five domain scores (model A.1), in each case excluding the two general facets. As the method of computing domain scores involves calculation of means of constituent facets, rather than simple summation of facet scores, different total scores may be obtained for different models.

Firstly, Pearson's product moment correlations were carried out for the datasets comprising the adults with intellectual disabilities, the general public adults, and their constituent subgroups. These correlations are presented in Table 10.50.

Table 10.50: Correlations of LEC and WHOQOL B+2 / A.1 Total Scores

Participant Groups and Subgroups	*N*	Correlations (Pearson's *r*)	
		Model B+2	Model A.1
All Adults with Intellectual Disabilities	417	0.378**	0.338**
Hospital Residents	213	0.173*	0.154*
Community Clients	204	0.415**	0.402**
All General Public	208	0.533**	0.490**
Public - ID subgroup	103	0.563**	0.508**
Public - BREF subgroup	105	0.500**	N/A

** Significant at 0.01 level (2-tailed) * Significant at 0.05 level (2-tailed)

For the groups of adults with intellectual disabilities, significant positive correlations were found between the LEC and the WHOQOL across both WHOQOL models. For the community clients, a moderate level of significant positive correlation (r = 0.4) was found between the measures; and for the hospital residents, a low significant positive correlation (r = 0.2) was obtained. Significant positive correlations were found between the two measures for all general public groups also. A higher significant positive correlation (r = 0.6) was obtained for the general public in relation to the LEC and the WHOQOL-ID for model B+2; and moderate significant positive correlations (r = 0.5) were found between both the LEC and the WHOQOL-ID for model A.1, and between the LEC and the WHOQOL-BREF for model B+2.

These correlations suggested that the degree of association between the two measures varied across the participant groups, with relatively lower correlations found between hospital residents' total scores, compared with moderate to high correlations found between the total scores of community clients and the general public.

This finding could not be accounted for in terms of the level of dependency of hospital residents compared with community clients, as the two groups of adults with intellectual disabilities were matched on this variable. However, as the impact of response mode on the quality of life scores had already been noted (and because the hospital group had the highest proportion of proxy respondents at 87%), partial correlations were carried out to control for the effect of direct or proxy response mode. These correlations are presented in Table 10.51.

Table 10.51: Partial Correlations of LEC and WHOQOL Total Scores (controlling for Response Mode)

Participant Groups and Subgroups	*N*	Partial Correlations	
		Model B+2	Model A.1
All Adults with Intellectual Disabilities	417	0.322***	0.284***
Hospital Residents	213	0.143*	0.132
Community Clients	204	0.326***	0.319***

*** Significant at 0.001 level (2-tailed) * Significant at 0.05 level (2-tailed)

When the effect of response mode was held constant for the groups of adults with intellectual disabilities, the disparity between the hospital residents and the community clients remained, although the level of correlation between the two measures fell slightly for both groups. A low to moderate significant positive correlation ($r = 0.3$) was obtained for the community clients for both models B+2 and A.1; a very low significant positive correlation ($r = 0.1$) was found for the hospital residents for model B+2; and a very low non-significant positive correlation was found for the hospital residents for model A.1.

As described earlier, on many dimensions of the two quality of life measures, the scores of hospital residents, community clients, and the public tended to conform to the pattern H < C < P. This relationship was demonstrated consistently for the total scores on both measures also.

As shown in Table 10.52, the mean total score of hospital residents on the LEC was 19, compared with 29 for community clients and 39 for members of the public. Similarly, on the WHOQOL-ID, the mean total score of hospital residents was 88, compared with 93 for community clients and 97 for the general public on model B+2, and 72, compared with 75 for community clients and 80 for the public on model A.1.

Table 10.52: LEC and WHOQOL Total Mean Scores and Standard Deviations

Measure / Model	Hospital (*N* = 213)			Community (*N* = 204)			Public (*N* = 208)		
	Range	Mean	*SD*	Range	Mean	*SD*	Range	Mean	*SD*
LEC	9-34	18.51	4.73	20-40	29.24	4.39	19-50	39.27	5.06
WHOQOL B+2	58-111	87.75	8.91	63-115	92.75	9.95	62-116	97.3	11.34
WHOQOL A.1	53-94	71.84	7.39	51-93	75.31	8.47	49-96	80.78	9.36

LEC: minimum = 0, maximum = 50; WHOQOL: minimum = 33, maximum = 165

In combination with the results of the correlations between the two measures across the participant groups, this tended to indicate that there were weaker associations between measures in the context of lower total scores i.e. that the correlations between the objective and subjective measures were not robust across the full score range. For these samples of participants, the greatest mean total score disparity was demonstrated in relation to the LEC (20% difference between adjacent groups). Thus, it seemed that lower objective life quality was neither consistently, nor systematically associated with *similarly* low levels of subjective quality of life.

These findings might be artefacts of variation in the psychometric properties of items within and between scales, for example the differential thresholds of items triggering response categories at different levels. However, within the context of the current study, hospital residents may have adapted, or habituated, to their adverse institutional circumstances to the extent that their relative impoverishment (particularly notable in relation to home environment, activities, freedom and opportunities) had only a relatively weak association with their subjective perceptions of life quality; and similarly, the enhanced and more normalised objective life conditions of the community clients had not been accompanied by a proportionate increase in subjective well-being. This explanation is consistent with homeostatic models of overall quality of life, which suggest that subjective well-being has a 'set point'. For example, Cummins (2000) suggests that homeostatic control is maintained by cognitive mechanisms at around 70% of the relevant scale maximum (with the normative range being within 60-80%) and functions to sustain positive feelings and motivation within a wide range of objective living conditions, up to the point where adverse conditions become so burdensome, or so unremitting, that environmental adaptation is impossible.

For many of the hospital group, the institution had been their home for most of their lives. The mean length of stay was 31 years (*SD* 15.2 years, range 1-82 years); only 23 residents (11%) had been in hospital less then ten years; and 19 people (9%) had lived there for over 50 years. In these circumstances a degree of habituation is unsurprising, particularly in the context of gradual environmental enhancement and care practice improvement over the years.

10.4 Open-Ended Quality Questions

The set of four open-ended questions were presented to all participants with exactly the same wording and open response format. There were some missing values in this qualitative dataset, but the rate was low. For four questions across 625 participants, there were only 59 missing values, representing 2.3% of all values. There were no missing values for the hospital or community groups, which suggested that both direct and proxy participants were able to respond readily to this format. However, for the general public group, there were varying rates of missing values on all questions: 3.9% (best thing in life); 7.2% (worst thing in life); 11.5% (thing to change about life); and 5.8% (ambition for future). This suggested that the item about whether there was anything they would like to change about their life might have presented problems for the public, although the rate of missing values on this item only just exceeded the criterion 10%.

The responses provided were varied, but were amenable to simple categorisation for further analysis. In the following set of summary tables, the themes are presented by overall total frequency; and for each participant group the most frequently cited theme is shown in red; the second most frequent theme in blue; and the third most frequent theme in pink.

Best Thing in Life

The responses to the question *'what is the best thing in your life?'* are presented in full in Tables A10.6 and A10.7 in Appendix 10, and extracts of the most frequently mentioned themes by participant group and response mode are shown in Tables 10.53 and 10.54.

Table 10.53: Best Thing in Life by Participant Group

BEST thing in life	Hospital		Community		General Public		Total	
	N	%	*N*	%	*N*	%	*N*	%
Family relationships	49	23.0	30	14.7	87	43.5	166	26.9
Community activities - outings	24	11.3	39	19.1	3	1.5	66	10.7
Current lifestyle - living arrangements	12	5.6	31	15.2	5	2.5	48	7.8
Leisure activities (in ward, home)	19	8.9	8	3.9	4	2.0	31	5.0
Staff relationships	15	7.0	15	7.4			30	4.9
Personal relationships - friends	8	3.8	3	1.5	15	7.5	26	4.2
Privacy - own room	8	3.8	15	7.4			23	3.7
Freedom – choice	5	2.3	11	5.4	6	3.0	22	3.6
Generally happy, content			1	0.5	20	10.0	21	3.4
	(*N* = 213)		(*N* = 204)		(*N* = 200)		(*N* = 617)	

As shown in Table 10.53, the best thing in the lives of hospital residents were family relationships (23%), community activities (11%) and ward based leisure activities (9%); also mentioned were staff relationships (7%) and current lifestyle (6%). For community clients, the best things were community activities (19%), current lifestyle (15%) and family relationships (15%); however, staff relationships (7%), privacy (7%) and freedom (5%) were mentioned also. The general public reported family relationships (44%) as the best thing in their lives, followed by general happiness or contentment (10%) and personal relationships (8%); however, health and fitness (7%), aspects of work (5%) and retirement (5%) were mentioned quite frequently also.

Interestingly, 15% of community clients, mentioned current lifestyle or living arrangements as a best thing in life, but only 6% of hospital residents and 3% of the public did so. Similarly, community activities was mentioned by 19% of community clients and 11% of hospital residents, but only 2% of the public cited this. Unlike 20 members of the public (10%), no hospital resident and only one community client reported that they were just generally happy or content.

Table 10.54: Best Thing in Life by Response Mode

BEST thing in life	Direct		Proxy		Total	
	N	%	*N*	%	*N*	%
Family relationships	17	23.0	62	18.1	79	18.9
Community activities - outings	19	25.7	44	12.8	63	15.1
Current lifestyle - living arrangements	5	6.8	38	11.1	43	10.3
Staff relationships	1	1.4	29	8.5	30	7.2
Leisure activities (in ward, home)	7	9.5	20	5.8	27	6.5
	(*N* = 74)		(*N* = 343)		(*N* = 417)	

As shown in Table 10.54, the responses of the direct and proxy subgroups were similar, with community activities (26%) mentioned most often as the best thing in life by clients themselves, followed by family relationships (23%) and home or ward based leisure activities (10%). Proxy staff reported family relationships (18%) as the best thing in the lives of the clients for whom they responded, followed by community activities (13%) and current lifestyle (11%).

Although the theme of staff relationships was not within the top three most frequently mentioned themes by either the hospital or community groups, it was mentioned by similar proportions (7%) of respondents (Table 10.53). However, it was noteworthy that only one adult with intellectual disabilities (1%) in either the hospital or community direct response subgroups cited this as a best thing in life, whereas 29 staff proxies (9%) surmised this to be the case (Table 10.54). In contrast, 7% of the direct subgroup mentioned personal relationships and friends as the best thing in their life, but this was mentioned by only 2% of the proxy respondents.

Worst Thing in Life

The responses to the question *'what is the worst thing about your life?'* are presented in full in Tables A10.8 and A10.9 in Appendix 10, and extracts of the most frequently mentioned themes by participant group and response mode are shown in Tables 10.55 and 10.56.

Table 10.55: Worst Thing in Life by Participant Group

WORST thing about life	Hospital		Community		General Public		Total	
	N	%	*N*	%	*N*	%	*N*	%
Health - fitness	47	22.1	44	21.6	34	17.6	125	20.5
Current lifestyle - living arrangements	30	14.1	33	16.2	5	2.6	68	11.1
Don't know/nothing	14	6.6	22	10.8	20	10.4	56	9.2
Work - job security	1	0.5	1	0.5	46	23.8	48	7.9
Personal relationships - friends	17	8.0	22	10.8	7	3.6	46	7.5
Community activities - outings	20	9.4	12	5.9			32	5.2
	(*N* = 213)		(*N* = 204)		(*N* = 193)		(*N* = 610)	

As shown in Table 10.55, hospital residents mentioned health and/or fitness (22%), current lifestyle and living arrangements (14%) and (lack of) community activities (9%) most frequently as the worst things in their lives; also noted were personal relationships (8%), their current ward (6%), (lack of) freedom and choice (5%), boredom (5%) and the prospective move related to the hospital closure plan (5%). For community clients the worst things were health and/or fitness (22%) and current lifestyle and living arrangements (16%) and personal relationships (11%) also; in addition communication difficulties (6%) and either lack of, or disliked, community activities (6%) were mentioned. The public reported aspects of work and job security (24%) as the worst thing in their lives, followed by health and/or fitness (18%), family relationships (9%), and issues of money and financial security (6%). Finally, similar proportions of community clients (11%) and the public (10%) were unable to think of a 'worst thing' to report.

Paradoxically, community activities or the lack of them appeared in both the best and worst lists for hospital residents; community clients reported elements of their current lifestyle and living arrangements as both best and worst things; and the public indicated that work and job security had both positive and negative influences on their lives. These unprompted and individually generated responses seemed to signal key aspects of life, which impacted significantly on the perceived quality of life of the participant groups.

For all three participant groups, health related issues were rated as one of the two worst things in their lives (consistent with the finding of similar health status between the groups). However, given that one group of adults with intellectual

disabilities lived in a hospital, and many of the other group were cared for by staff from a nursing background, and were in receipt of health services from visiting community teams, this finding seemed to suggest there might be cause for concern.

Table 10.56: Worst Thing in Life by Response Mode

WORST thing about life	Direct		Proxy		Total	
	N	%	*N*	%	*N*	%
Health - fitness	7	9.5	84	24.5	91	21.8
Current lifestyle - living arrangements	13	17.6	50	14.6	63	15.1
Personal relationships - friends	7	9.5	32	9.3	39	9.4
Don't know/nothing	12	16.2	24	7.0	36	8.6
	(*N* = 74)		(*N* = 343)		(*N* = 417)	

As shown in Table 10.56, the responses of the direct and proxy subgroups were fairly similar. Clients themselves mentioned current lifestyle and living arrangements (18%) most frequently as the worst thing in their lives, followed by health and/or fitness (10%), personal relationships (10%), current ward (8%, hospital residents only), food/drink (5%) and (lack of) freedom (5%). Proxy staff reported health and/or fitness (25%) as the worst thing in the lives of the clients for whom they responded, followed by current lifestyle and living arrangements (15%), personal relationships (9%) and (lack of) community activities (9%). On a more positive note, 16% of direct clients and 7% of proxy respondents were either unable to think of a 'worst thing', or said there was nothing.

Although health related issues were reported as the worst thing in their lives by similar proportions of the hospital and community groups (22%), only 10% of direct clients mentioned health issues, compared with 25% of proxy staff. Therefore this finding may reflect a range of complex health issues related to the higher levels of dependency of clients for whom proxy responses were provided.

Thing to Change in Life

The responses to the question *'is there anything you would like to change about your life?'* are presented in full in Tables A10.10 and A10.11 in Appendix 10, and extracts of the most frequently mentioned themes by participant group and response mode are shown in Tables 10.57 and 10.58.

As shown in Table 10.57, approximately 43% of all participants could not think of anything they wanted to change about their lives, or said there was nothing they wanted to change. For the hospital and community groups this was not unexpected, given the proportion of proxy staff respondents, and thus the associated potential impact of both cognitive dissonance and patterns of socially desirable responding.

Table 10.57: Thing to Change by Participant Group

CHANGE about life	Hospital		Community		General Public		Total	
	N	%	*N*	%	*N*	%	*N*	%
Don't know/nothing	87	40.8	93	45.6	78	42.4	258	42.9
Health - fitness	17	8.0	21	10.3	23	12.5	61	10.1
Community activities - outings	31	14.6	15	7.4	1	0.5	47	7.8
Work - job security	1	0.5	1	0.5	29	15.8	31	5.2
Current lifestyle - living arrangements	11	5.2	10	4.9	9	4.9	30	5.0
Family relationships	9	4.2	13	6.4	6	3.3	28	4.7
	(*N* = 213)		(*N* = 204)		(*N* = 184)		(*N* = 601)	

In relation to things that they would like to change, hospital residents mentioned community activities (15%), health and/or fitness (8%) and current lifestyle and living arrangements (5%). Community clients mentioned health and/or fitness (10%) and community activities (7%) also, along with family relationships (6%) and current lifestyle and living arrangements (5%). The public wanted to change their health and/or fitness (13%) also, but a higher proportion of the public reported aspects of work or job security (16%) as something they would like to change, and cited money and financial security (7%) and their current lifestyle and living arrangements (5%) also. These findings were consistent with the participant groups' reports of the worst things in their lives.

Table 10.58: Thing to Change by Response Mode

CHANGE about life	Direct		Proxy		Total	
	N	%	*N*	%	*N*	%
Don't know/nothing	35	47.3	145	42.3	180	43.2
Community activities - outings	7	9.5	39	11.4	46	11.0
Health - fitness	2	2.7	36	10.5	38	9.1
Family relationships	1	1.4	21	6.1	22	5.3
Current lifestyle - living arrangements	4	5.4	17	5.0	21	5.0
	(*N* = 74)		(*N* = 343)		(*N* = 417)	

As shown in Table 10.58, similar proportions of direct and proxy respondents could not think of anything they wanted to change about their lives, or said there was nothing they wanted to change; and similar proportions (10% direct, 11% proxy) mentioned a desire for change in relation to community activities, and current lifestyle and living arrangements (5%). However, proxy staff suggested health related issues (11%) and family relationships (6%) for change more often than direct clients (3% and 1% respectively).

Future Ambition

The responses to the question '*what would you like for the future?*' are presented in full in Tables A10.12 and A10.13 in Appendix 10, and extracts of the most frequently mentioned themes by participant group and response mode are shown in Tables 10.59 and 10.60.

Table 10.59: Future Ambition by Participant Group

Future Ambition	Hospital		Community		Public		Total	
	N	%	*N*	%	*N*	%	*N*	%
Don't know/nothing	21	9.9	58	28.4	1	0.5	80	13.1
Good health, improved health, continued health, remain active, be fitter	2	0.9	17	8.3	54	27.6	73	11.9
Home, community house, small home, new home, remain in	46	21.6	14	6.9	8	4.1	68	11.1
Environment, quieter, smaller, secure, structured, comfortable, familiar	49	23.0	3	1.5			52	8.5
Live elsewhere, live on own, live with specified others	21	9.9	8	3.9	2	1.0	31	5.1
More activities, social life, more outings, visit friends	9	4.2	17	8.3	2	1.0	28	4.6
Stability, continuity, be settled, things to stay same, enjoy status quo	9	4.2	11	5.4	5	2.6	25	4.1
Holidays, more holidays, travelling			17	8.3	4	2.0	21	3.4
Financial security, more money, pension, win lottery			2	1.0	17	8.7	19	3.1
Happiness, happy life	1	0.5	4	2.0	13	6.6	18	2.9
Work, better job, more satisfying work, job security, success, promotion			2	1.0	14	7.1	16	2.6
More contact with family	9	4.2	5	2.5	1	0.5	15	2.4
More individual attention, with familiar people	6	2.8	9	4.4			15	2.4
Retirement, early, happy, long					14	7.1	14	2.3
	(*N* = 213)		(*N* = 204)		(*N* = 196)		(*N* = 613)	

As shown in Table 10.59, the most frequently cited ambition of the hospital group was for a different living environment: e.g. a quieter, smaller, secure, more comfortable environment (23%), a home in the community (22%), or somewhere else on their own or with specified others (10%). In contrast, a quarter of the community group could not think of anything they wanted for the future, or reported no particular ambition; thereafter, community clients mentioned ambitions for better health (8%), more social and leisure activities (8%), more holidays (8%), a desire to remain in the community (7%), and for stability and continuity (5%). The most frequently reported ambition of the public was for better health and/or fitness (28%), but financial security (9%), better or more satisfying work (7%), and retirement (7%) were mentioned also. These findings were broadly consistent with responses to other items in the set also.

As shown in Table 10.60, similar proportions of direct and proxy respondents could not think of anything they wanted for the future, or cited no ambition (20% and 19% respectively). A higher proportion of clients themselves reported ambitions for community homes (20% compared to 13% proxies), living elsewhere (15% compared to 5% proxies) and holidays (11% compared to 3% proxies); but a higher proportion of proxies mentioned a different environment (15% compared to 1% direct) the location of which was unspecified.

Table 10.60: Future Ambition by Response Mode

Future Ambition	Direct		Proxy		Total	
	N	%	*N*	%	*N*	%
Don't know/nothing	15	20.3	64	18.7	79	18.9
Home, community house, small home, new home, remain in	15	20.3	45	13.1	60	14.4
Environment, quieter, smaller, secure, structured, comfortable, familiar	1	1.4	51	14.9	52	12.5
Live elsewhere, live on own, live with specified others	11	14.9	18	5.2	29	7.0
More activities, social life, more outings, visit friends	4	5.4	22	6.4	26	6.2
Stability, continuity, be settled, things to stay same, enjoy status quo	5	6.8	15	4.4	20	4.8
Good health, improved health, continued health, remain active, be fitter	2	2.7	17	5.0	19	4.6
Holidays, more holidays, travelling	8	10.8	9	2.6	17	4.1
	(*N* = 74)		(*N* = 343)		(*N* = 417)	

Finally, direct clients mentioned a desire for stability and continuity (7%); similar proportions of direct and proxy respondents had ambitions for more leisure and social activities (5%); and staff wished for good or better health (5%) for the clients for whom proxy responses were provided.

Summary

The overall pattern of responses to the four open-ended questions was relatively consistent across the participant groups. Family relationships, community activities and current lifestyle were reported as the best things in peoples' lives; health and current lifestyle tended to be the worst things in peoples' lives; many people were uncertain of what they wanted to change about their lives, or did not wish for any change, although health and fitness was a common concern; and similarly, many people were uncertain of their ambition for the future, or reported no particular direction, although improved health and different types of home or environment were mentioned quite frequently.

These results were consistent with the findings from pilot study two, in which relationships, home and activities were common response themes in respect of all four questions (Chapter 6); and similar to the quality of life themes rated as the most important in people's lives in pilot study one (Chapter 5).

10.5 Comparative Quality of Life

As described in Chapter 8, two additional comparative quality of life questions were presented to general public participants only, using exactly the same format in both versions of the assessment booklet. These items invited general public participants to: compare their quality life with that of other people in their neighbourhood; and compare their quality of life with that of people with intellectual disabilities.

The public's responses to these items are presented in Table 10.61.

Table 10.61: General Public Quality of Life Comparisons

QOL comparison	Much worse		A bit worse		About the same		A bit better		Much better	
	N	%	*N*	%	*N*	%	*N*	%	*N*	%
Public v Others	1	0.5	15	7.3	103	50.0	63	30.6	24	11.7
Public v ID Adults	1	0.5	3	1.5	7	3.4	49	24.1	143	70.4

Missing Cases: comparison with others = 2, comparison with ID = 5

In relation to both the comparison with peers, and the comparison with adults with intellectual disabilities, over 90% of the public participants reported their own quality of life to be about the same as, or better than, that of others. However, the frequency distribution between the different response categories varied markedly for the comparator groups.

Exactly half of the public group reported that they thought their quality of life was about the same as that of other people living in the same neighbourhood; although four out of ten public participants thought their quality of life was a bit better (31%) or much better (12%) than that of others; and one in twelve thought their quality of life was a bit worse (7%) or much worse (1%) than that of others.

However, only three in a hundred members of the public reported that they thought their quality of life was about the same as that of adults with intellectual disabilities; while more than nine out of ten public participants rated their quality of life as a bit better (24%) or much better (70%) than that of ID adults; and only two in a hundred people thought their quality of life was a bit worse (1%) or much worse (2%) than that of adults with intellectual disabilities.

These findings seemed to provide a further illustration of the potential influence of 'downwards' social comparisons (previously noted in connection with staff proxies) as the public's perceptions of their own superiority, or of the differences between themselves and adults with intellectual disabilities, enhanced evaluation of their comparative life quality.

The extent to which members of the public might have responded within the context of such a schema ('...I must be better off than someone who has a learning disability') may be linked to their general beliefs about the impact of intellectual disabilities on quality of life, or may be related to the opportunities for comparisons afforded by their direct experience of specific individuals with intellectual disabilities. Therefore, the extent of public participants' contact with the people with intellectual disabilities was examined also.

10.6 General Public Contact with Intellectual Disabilities

The two final questions presented to all general public participants collected information about their type of contact (if any) with individuals with intellectual disabilities. These data provided an indication of the extent to which members of the public had contact with intellectually disabled people in their local community, and were of specific interest as the recruitment of the public participants was based on matched residential locality with the group of community clients.

The public participants' experience of people with intellectual disabilities by contact type is presented in Table 10.62; and a summary of their contact with the client group by total number contact types is presented in Table 10.63.

Table 10.62: Public Group Contact with Intellectual Disabilities

Contact with ID?			Local community		Workplace		Social acquaintance		Neighbour		Friend		Family member	
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Yes	110	53.4	41	19.9	34	16.5	17	8.3	22	10.7	20	9.7	44	21.4
No	96	46.6	165	80.1	172	83.5	189	91.7	184	89.3	186	90.3	162	78.6

Missing Cases: 2

As shown in Table 10.62, approximately half of the public group (53%) had some direct contact with one or more individuals with intellectual disabilities. The majority of these direct contacts were with a family member (21%), or were experienced within the local community (20%) or in the workplace (17%); in addition, there were approximately equal numbers of contacts with a person with intellectual disabilities who was a neighbour (11%), a friend (10%) or a social acquaintance (8%).

As shown in Table 10.63, the majority of the public group who reported direct experience of people with intellectual disabilities mentioned a limited number of contact types.

Table 10.63: Public Group Contact with Intellectual Disabilities By Total Contact Types

Total Number of Contact Types													
0		1		2		3		4		5		6	
N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
96	46.6	65	31.6	32	15.5	6	2.9	5	2.4	1	0.5	1	0.5

Missing Cases: 2

One third of the public mentioned one contact type only (representing 59% of those with contact experience); one eighth reported two contact types (representing 29% of those with contact experience); and only one person in seventeen mentioned three or more contact types (12% of those with contact experience).

These data indicated that around 80% of the public's contact with people with intellectual disabilities (excluding that with family members) took place within the local community, in the context of work or social networks, suggesting that community clients had established some degree of community presence. However, approximately 90% of the public's contact experience was limited to one or two settings or contact types, suggesting that for many individuals with intellectual disabilities, only partial integration to a typical range of social roles had been realised.

10.7 Summary and Conclusions

This study investigated the quality of life of adults with intellectual disabilities in hospital and community settings and compared both groups with general public counterparts matched for age, gender and health status. The two groups of adults with intellectual disabilities were matched for level for dependency also; and the community and public group were matched for residential locality. Two complementary quality of life instruments were employed in the comparison, an objective measure, the Life Experiences Checklist (2nd Edition, Ager, 1998); and a broadly subjective measure, the WHOQOL-ID, adapted from the WHOQOL-BREF (WHOQOL Group, 1998a) and developed for an intellectual disabilities population within the course of the study. In addition, a brief housing survey was carried out to explore the quality of the social care accommodation of the community group of adults with intellectual disabilities.

The Measurement of Quality of Life in Intellectual Disabilities

There were three key aspects of the approach to measurement of quality of life within the study: the generation of quality of life facets; the performance of the adapted WHOQOL-ID; and aspects of the scale format and administration.

Quality of Life Facets

The themes relevant to assessment of quality of life in intellectual disabilities were generated empirically by focus groups of adults with intellectual disabilities, staff working in the specialty, and relatives of ID adults. In addition, the focus groups provided suggestions for scale items and response formats. This ensured that three potential categories of target respondents for the subsequent instrument were involved in the conceptualisation and development of the

WHOQOL-ID (as recommended by Day and Jankey, 1996). The iterative procedure employed was drawn from the original methodology of the WHOQOL Group (Szabo, 1996), and reflected a departure from scale developments underpinned by conceptual frameworks derived from extant literature only (e.g. Cummins, 1993).

Of the 59 themes identified by the focus groups, 42 (71%) were core themes that were represented in the facets of the WHOQOL-BREF; and 17 (29%) were supplementary to the existing instrument. There was convergence of two or more focus group types in relation to 78% of themes generated. All WHOQOL facets were endorsed as relevant to the quality of life of adults with intellectual disabilities also, which was consistent with the suggestion that the instrument reflects conceptual universality (WHOQOL Group, 1998b; Power et al, 1999). Individual ratings of the relative importance of themes to the quality of life of adults with intellectual disabilities made by focus groups members were similar to that found in other studies, with primacy accorded to personal relationships (Sandhu, 1996; Cummins, 2002).

The supplementary quality of life themes seemed to reflect positive and negative expressions of five social justice dimensions: social devaluation; discrimination; social equity; empowerment and self-determination; and social acceptance. These dimensions had face validity as a result of the empirical method of identification, and were consistent with the conceptual literature (e.g. Hughes et al, 1995; Shalock, 2004). Various formulations of some of the component facets were included in other population specific quality of life scales (e.g. Shalock and Keith, 1993). However, it appeared that none of the currently available scales measured *all* of the dimensions and facets.

Performance of WHOQOL-ID

As a result of the focus group work, a number of modifications were made to the WHOQOL-BREF in order to adapt it for adults with intellectual disabilities. These included simplification of item wording, corresponding revision of response scales, augmentation of the response format by 'smiley faces', and preparation of new items to reflect the additional facets generated. Following pilot testing, a 36-item WHOQOL-ID (26 revised core items and 10 new items) was completed by, or on behalf of, 213 hospital residents, 204 community clients and 103 members of the general public. A further 105 public participants completed the WHOQOL-BREF (original item wording) supplemented by the new items.

Overall, the psychometric properties of the WHOQOL-ID were found to be adequate within the context of a new scale in the first stage of development (see Hair et al, 1998). There were very low rates of missing values within the samples (0.8% overall), suggesting that most participants found the item wording straightforward and the content of acceptable sensitivity. A number of items demonstrated frequency problems, of which some could be accounted for by

participant characteristics, but others were more likely to be indicators of possible of problem items. Adequate internal consistency was demonstrated across all participant groups ($\alpha \geq 0.6$), and in both direct and proxy response modes ($\alpha \geq 0.5$). The reliability analysis suggested that one of the ten new items lacked reliability and should be dropped in its current format, and that the originally hypothesised single supplementary domain performed slightly better as two separate domains of six and three items. The correlation analysis showed that all core items, and all but one supplementary item, loaded highest on the predicted domain, suggesting the genuinely supplementary nature of the new items; the exception being the same new item identified as problematic in the reliability analysis. Although a varying number of lower correlations with non-predicted domains were found, many of these could be accounted for in terms of item content, facet definition or participant characteristics. Within the supplementary module, superior item-domain correlations were found for the two-domain structure, which supported the finding from the reliability analysis.

Exploratory factor analysis suggested the nine new items comprised two factors, broadly reflecting empowerment and social inclusion. However, in combination with core items, possible five- or six-factor solutions emerged, with a separate and distinct social inclusion factor evident in each. Neither solution reflected the domain configuration of the original WHOQOL-BREF. With this sample of the intellectual disabilities population, the amalgamation of core and new items produced factors which seemed to reflect social and emotional care and support, functional ability, physical and mental health, empowerment and participation (either separately or in combination) and social inclusion. These factors were consistent with the characteristics of the ID clients and their backgrounds in cared-for environments. Confirmatory factor analysis supported the exploratory factor solutions. However, the fit indices obtained from the structural equation modelling of the empirically derived five- or six-domain 'ID' models were only slightly superior to the six-domain 'WHOQOL-BREF and supplementary module' model, (with CFIs approximating to 0.8, and χ^2 values remaining significant), and it was noted that a split-half design with a very much larger sample would be required to establish the best fitting model unequivocally.

Finally, three items (6, spirituality; 21, sexual activity/special relationship; and 26, negative feelings), and two response scales (for items 7, thinking; and 11, body image), were identified in several analyses as requiring revision or modification prior to inclusion in a subsequent version of the instrument.

Format and Administration of the WHOQOL-ID

Experience gained from both the pilot and main studies suggested that the adults with intellectual disabilities who participated directly were able to respond to the five-point Likert scales without difficulty, a finding consistent with other reports (Cummins, 1997; Verri et al, 1999). Feedback about the pilot instrument indicated that 100% of the pilot ID client sample found the 'smiley faces' helpful, and 92% thought the questions they had been asked were relevant to

their lives. The pilot work demonstrated mean scale administration times of approximately 30 minutes for ID clients, and 20 minutes for proxies, which were broadly in line (pro rata for item number) with guidance provided in the Draft WHOQOL Manual (WHO, 1998). These were confirmed by experience in the main study and indicated that the scale was practicable for the target population.

The Quality of Life of Adults with Intellectual Disabilities in Scotland

Three aspects of the quality of life of adults with intellectual disabilities were investigated: the quality of community clients' social care accommodation, the preferred service model in Scotland from 2005 (Scottish Executive, 2000), was surveyed; the objective life conditions/experiences of hospital residents and community clients was measured and compared with that of the general public; and the subjective life satisfaction of hospital residents and community clients was assessed and compared with that of the general public also.

Quality of Accommodation

The subsidiary study of community accommodation was commissioned by a housing agency. The characteristics of 51 community projects were surveyed and project staff views about the suitability of the accommodation to meet clients' need were explored. (A full summary of this subsidiary study, together with a discussion of the findings and the conclusions drawn, was presented at the end of Chapter 7).

The community projects were all relatively small (nine places or fewer) and located in a wide variety of accommodation including flats, houses and bungalows, in urban and rural settings. Approximately 80% of the project accommodation was either purpose built, or specially adapted, to meet the needs of the ID clients; 60% was located in ground-floor dwellings; and many contained specialist features or equipment consistent with the dependency of the residents.

A pilot housing fit index (HFI) was developed within the study and used to assess the degree of fit between the accommodation and clients' needs. This measure was based on a restricted set of variables, limited by the scope of the study, but seemed to discriminate between projects to some extent. Overall, the mean HFI for the 51 projects was 74% of the scale maximum; 12% of projects achieved an HFI one standard deviation above the mean; 16% scored one standard deviation below the mean; and 6% of projects scored two standard deviations below the mean. HFI score differences did not appear to be related to many of the variables measured as part of the subsidiary study (e.g. project size, type, location, duration). However, significant differences in HFI were found in relation to projects experiencing contemporaneous problems with immediate neighbours or the local community. This finding must be interpreted with caution given the small sample size, but was of interest in relation to the findings

of other studies that showed neighbours' willingness to provide practical assistance to community projects decreased over time (McConkey et al, 1993), and that many people with intellectual disabilities suffered victimisation by members of their local communities (Flynn, 1989).

Objective Quality of Life

Comparison of the objective quality of life of adults with intellectual disabilities and the general public indicated that both hospital residents and community clients had a more limited range of life conditions and experiences than the public. Significant differences were found between the three groups on all subsections of the LEC (home, leisure, relationships, freedom and opportunities) and in respect of total scores. The uniform direction of differences revealed the significantly poorer objective life quality of community clients compared with their general public counterparts, but also the significantly more impoverished quality of life of hospital residents compared with both groups.

Within the framework of matched age, gender and dependency, and similar institutional background, the differences found between hospital residents and community clients suggested that relocation from hospital to community was associated with improved objective quality of life. This was consistent with the findings of other studies that have used measures of objective life quality. For example, both Cullen et al (1995), and Ager et al (2001), reported higher quality physical environments in the community compared with hospital. Dagnan et al (1995) reported a significant increase in scores on all eight subscales of the *Questionnaire on Quality of Life* (Cragg and Harrison, 1984), and found that clients in the community were living in ordinary houses, had a wider range of leisure activities, were less governed by routines imposed by others, had more control over aspects of their lives (e.g. buying food, doing domestic chores), and made more day-to-day decisions than when they resided in a hospital. Using a short form of the same instrument, Dagnan et al (1998) found improvements in the quality of life of older adults with intellectual disabilities in the first 41 months after leaving hospital, a general plateau effect after 53 months, but a significant reduction in the amount of choice offered to individuals between the two time points.

However, the differences found between community clients and members of the public, who were of similar age and gender, and living in similar local communities, suggested that relocation had not enhanced the life conditions and experiences of the community group to the level enjoyed by other members of society. This finding was disappointing, but not surprising. In a study of adults with intellectual disabilities living alone in the community, some of whom had been former hospital residents, Donegan and Potts (1988) found that community life was associated with physical integration but little community integration, reporting relatively infrequent use of community facilities, limited opportunities for social interaction, and concluding that many ID clients 'live on the fringes of society' (p.21).

The data on general public contact with people with intellectual disabilities in the current study tended to support this. Over half of the general public group had some contact with individuals with intellectual disabilities, of which around 80% was non-familial contact in local community networks. This indicated that ID clients had established some physical community presence; however, 90% of the reported contact was restricted to one or two settings only, suggesting that social integration was limited.

In this context, Duvdevany (2002) found that the physical self-concept of people with intellectual disabilities who participated in segregated activities was higher than for those who took part in integrated activities; but those who participated in integrated activities were more satisfied with their self-concept. This finding was consistent with social comparison theory (Festinger, 1954), and suggested that when individuals with intellectual disabilities compared themselves to people without disability in integrated settings, their self-concept may have been negatively affected; but in segregated environments, comparisons with others related to people with disabilities also, such that greater satisfaction with self-concept was preserved. This finding illustrates the links between objective life conditions and subjective well-being, and suggested that the relative lack of social integration of people with intellectual disabilities may be accounted for in a number of ways, not associated solely with the disposition of the community.

Ager et al (2001) found significant differences in the LEC subsection and total scores of clients following transfer to the community, but scores on the relationships and freedom subsections remained well below general population norms, representing 'a failure to achieve core elements of the stated vision for non-institutional re-provisioning' (p.398). In the present study, the community group fell below general population norms on the LEC relationships and freedom subsections also. For example, only one in three community clients had 'several' close friends (defined by coding guidance as more than two); only two in a hundred had a partner; and only one in a hundred had friends to stay at least once a year. Clegg and Standen (1991) suggested that friendships between people with intellectual disabilities may be relatively shallow, but found that those who had peer-group friends were significantly more likely to describe themselves positively than those without a friend. Knox and Hickson (2001) carried out in-depth interviews with people with intellectual disabilities to explore the meaning of friendship and close relationships in their lives. In contrast, they found that the friendships described as close were usually longstanding, pivotal in the current lives and shared history of the individuals, and invariably with other ID clients; but typical relationships with non-disabled people were more superficial and of shorter duration. This study involved a very small sample of adults with intellectual disabilities, but it illuminates the potential for relocation to impact on important shared histories and patterns of friendship that may take a long time to re-establish.

Subjective Quality of Life

Comparison of the subjective quality of life of adults with intellectual disabilities and the general public revealed a more varied picture; and similar levels of subjective well-being were reported for community clients and the public on a number of individual facets and aggregate domains of the WHOQOL-ID.

Considering the findings in relation to the original WHOQOL model established for general adults, i.e. the 'WHOQOL-BREF and supplementary module' configuration, significant differences in subjective quality of life were found between hospital residents, community clients and the public on all six domains. Similar subjective quality of life was found for community clients and the public on the social, environment and empowerment domains; but significantly poorer subjective life quality was found for hospital residents on all three domains. However, on the psychological domain, both groups of adults with intellectual disabilities demonstrated similar, and significantly lower, psychological well-being compared to the public. On the physical domain, the significant differences reflected the pattern found for objective quality of life i.e. significantly poorer physical well-being was found for hospital residents than for community clients, but the public reported significantly superior physical well-being compared to both groups of adults with intellectual disabilities. The findings for the social inclusion domain exhibited the same overall trend, but in this case the differences between groups were smaller and only significant in relation to the comparison of hospital residents and the public; while it appeared that community clients and the public experienced similar levels of social inclusion, this finding suggested that hospital residents and community clients experience of social inclusion was similar also.

Overall, the differences found between hospital residents and community clients suggested that relocation from hospital to community was associated with enhanced subjective quality of life, and with levels of subjective well-being similar to that of other members of society in terms of social relationships, environmental circumstances and empowerment. These outcomes were broadly consistent with findings from other studies. For example, Janssen at al (1999) reported that social integration, freedom and self determination was more evident in children and adults in community homes compared with those living on the grounds/edge of residential facilities and supported by the 'mother' institution. However, community relocation seemed to have less impact on both physical and psychological well-being. This latter finding was interesting in the context of a study by Lundsky and Benson (2001), which suggested that the health and well-being of adults with intellectual disabilities in community settings was influenced by perceived social support and interpersonal relationships.

Generally higher levels of satisfaction with community lifestyles have been reported in a number of studies, and on a range of subjective life quality dimensions (Stanley and Roy, 1988; Knapp et al, 1992; Walker et al, 1993; Cullen et al, 1995). Using an 'open question' format similar to that of the present

study, Forrester-Jones et al (2002) found the most frequently reported positive features of community living were the living environment itself, the social setting and personal independence. However, different aspects of these same dimensions were frequently reported as negative features of community life also e.g. problems with neighbours in the local environment, problems with fellow residents in the social setting, or restrictions on freedom. In the current study similar associations were found between the community clients subjective perceptions of the best, and worst, things in their lives. Overall, community activities, current lifestyle and relationships were mentioned most frequently as positive aspects of community clients' lives; but health/fitness, current lifestyle and living arrangements, and personal relationships were mentioned most frequently as negative features. These findings are of particular relevance and interest, since open questions have been suggested to elicit more valid responses than closed and structured questions (Sigelman et al, 1981; Atkinson, 1988).

Despite the variations found across the domains, on the general facet of *overall quality of life*, community clients were found to have significantly superior subjective quality of life compared to hospital residents, and levels of subjective well-being similar to that of their non-intellectually disabled general public counterparts living in similar local neighbourhoods. Verri et al (1999) reported similar levels of subjective quality of life for groups of community clients and the general public in both Italy and Australia, and noted that the lack significant of differences was consistent with predictions based on a model of homeostatic control of subjective well-being (Cummins, 1998, 2000). The findings of the current study provided some support for this model, as similar levels of subjective well-being were found for the community and public groups, in the context of significantly poorer objective life quality demonstrated for community clients than the public on the LEC. The generally poor correlation between objective circumstances, and subjective quality of life, found in the current study was reported by Hensel et al (2002) also. Although the community group and the public were found to have similar levels of subjective quality of life, and approximately half of the general public group reported their own quality of life to be about the same as that of other people in their neighbourhood, only three in a hundred rated their quality of life as similar to that of people with intellectual disabilities. It was suggested that this finding might be accounted for in terms of downward social comparisons. This was consistent with the general model of social comparison (Festinger, 1954) and the findings of Skevington (1994) that social comparison processes were employed in thinking and decision-making about quality of life, and that downward social comparisons were made more frequently than upward comparisons.

Use of Proxies

A comparison of the relationship between direct and indirect reports of quality of life was not an integral part of the design of the current study. The requirement for proxy responding was driven inevitably by the characteristics of the index community cohort around which the study was planned.

The use of proxies has been controversial in the assessment of the quality of life of people with intellectual disabilities (Helm, 2000). In relation to both objective and subjective quality of life, some response mode differences were noted in the current study, although these were approached cautiously given the very small numbers in the direct response subgroups. Generally, clients with the capacity to respond directly seemed to report superior objective life conditions and experiences, and superior subjective quality of life on some domains (but not all constituent facets), compared to proxy respondents' reports provided for those without the ability to participate directly. However, relatively weak associations were found between level of dependency and scores on both the LEC and WHOQOL-ID. This suggested that response mode differences might be related to social processes, such social comparisons (in respect of the lower levels of proxy reports) and social desirability or cognitive dissonance (in relation to higher levels of proxy reports).

Schwartz and Rabinovitz (2003) reported that the life satisfaction scores of community clients and their staff were positively and significantly correlated, supporting the view that proxy reports could be used if no other alternative was available. However, they found some differences between the paired informants' reports also, which were related to the characteristics of the ID clients. Stancliffe (1999) suggested that differences between self- and proxy reports might not indicate the unreliability of one or other response mode, but may reflect genuine differences in perception. In this context, Schwartz and Rabinovitz (2003) found that self-reports by the same group of adult community clients and those of their parents acting as proxies were positively and significantly correlated also, but no significant differences were found between the mean scores of clients and parents, suggesting a greater similarity of perceptions associated with the close relationship and continued involvement of these parents. On this basis, parents may be regarded as the preferred informant to provide quality of life information for ID clients without the capacity to self-report. However, many people with intellectual disabilities with a background of institutionalisation, or in contemporaneous social care, lack contact with parents, or may not enjoy close relationships, and in the current study, this was not a viable option.

Policy and Service Implications

The study findings were consistent with the literature, and provided additional support for the direction of social policy towards the closure of institutions for people with intellectual disabilities, and the replacement of hospital based residential services with social care and support delivered in community settings. The relative impoverishment of hospital residents' objective life circumstances and life experiences, compared with that of community counterparts, was demonstrated clearly; and the impact of relocation on subjective perceptions of well-being in relation to social relationships, environmental circumstances and empowerment was evident also.

The similarity of the physical and psychological well-being of both hospital and community clients seemed to suggest that, following resettlement, the health-related quality of life of adults with intellectual disabilities remained relatively impoverished compared to that of other members of society. However, the lower subjective quality of life scores noted on some physical and psychological facets may have been associated with the presence of health problems (e.g. use of medication for epilepsy or mental health problems), or the various characteristics of the client group (e.g. the presence of cognitive impairments and related physical disabilities). Nevertheless, the finding of the desire of many of the adults with intellectual disabilities to improve aspects of their health and fitness (rated as one of the worst features of their lives) indicated the importance of health promotion and health service delivery in community settings, and suggested that the focus of health teams' interventions might require redefinition to include a perspective on everyday client-centred health issues, as well as more major illness and crisis interventions.

Nevertheless, the objective life quality of the community clients remained significantly poorer than that of general public counterparts; some aspects of subjective well-being failed to reach the level of other members of society; and the fit between clients' needs and their accommodation was found to be poor in some cases. This suggested that relocation to the community was far from being the end of the service or policy agenda. For example, the study found that aspects of social injustice remained evident e.g. community clients reported similar levels of discrimination as hospital residents, which were significantly higher than that experienced by public counterparts; and satisfaction with personal relationships was similar for both groups of ID adults, and significantly lower than for the general public.

Overall, the study highlighted the need for social policy and service development effort to continue and complete the current programme of de-institutionalisation, potentially involving a second generation of community care projects, deriving from the experience of the current programme; and to refocus on areas of unmet health and social need and remaining social injustice.

Research Process

The research methods employed in the study, and the overall research process, had a number of strengths. The detailed iterative procedure used to develop the WHOQOL-ID was robust and well documented; and was consistent with guidance from the literature to involve the target population in conceptualisation and scale development. The version of the measure used in the main study included additional dimensions, was broader and more comprehensive (arguably) than many existing scales, but retained the core WHOQOL facets associated with the notion of universal quality of life. The size of participant samples was large overall, and was equally divided between the three study groups, affording

a balanced between-groups design; and providing adequate statistical power. Furthermore, the achievement of group matching on three key planned variables, and one additional serendipitous variable, enhanced the validity and reliability of the comparisons. Finally, the study described a complete process from the initial generation of quality of life themes, through the development and piloting of the adapted measure, including the analysis of its psychometric properties, to its subsequent use with adults with intellectual disabilities in two settings, and related comparison with the original instrument with a general adult population. The resultant WHOQOL-ID requires a number of revisions and modifications, but may have the potential to contribute to practice in the assessment of quality of life in intellectual disabilities.

However, the study had a number of limitations and weaknesses also. A within-subjects repeated measures design might have conferred advantages, and a longitudinal design might have provided the opportunity for investigation of the consistency and durability of treatment or setting effects, but neither was feasible in the context of the study. Also, the employment of a second subjective quality of life measure would have allowed for examination of the criterion-related validity of the WHOQOL-ID, an element missing from the developmental process. The dependency measures employed were selected for convenience, as existing dependency data were available on many clients. However, only aggregate (rather than raw) data were available for the majority of community clients, limiting potential for between group comparisons at the level of items e.g. in relation to supplementary items on sensory deficits. Matching the groups of adults with intellectual disabilities for levels of intellectual functioning (as well as dependency linked to care needs) would have been desirable, but would have required considerably more time to complete new assessments, as the majority of ID clients had no contemporaneous cognitive assessment, and for some of the more severe and profoundly disabled adults, the reliability of IQ and related social adaptive measures may have been questionable. With hindsight, the study was flawed by a few mistakes that were occasioned by allowing design evolution after the study was embarked upon. For example, the comparison of the WHOQOL-ID and WHOQOL-BREF carried out with the matched split halves of the public group would have been more robust if this comparison had been considered and incorporated into the design at the outset i.e. avoiding the within study changes that were required to the non-scoring examples in the measures and to one response scale descriptor. The design of the WHOQOL-ID could have included an introductory test of the capacity of ID adults to respond to the five-point Likert scales (e.g. as employed in the ComQol, Cummins, 1993), which would have provided more robust evidence of the applicability of the scales (in augmented format) for the client group. Finally, if time and the staffing arrangements of hospital wards and community homes had permitted, proxy assessments could have been carried out by paired staff, and staff assessments could have been duplicated for a sample of clients able to respond directly also, to further investigate the reliability of proxy assessments of objective and subjective quality of life.

Research Recommendations

A number of research recommendations emerge from the consideration of the research process of the current study as described above.

Given the tremendous range of cognitive and communicative competency among people with intellectual disabilities (Felce and Perry, 1995), perhaps the most important lines of future research relate to the requirement to explore the most appropriate wording of items (e.g. the discarded advocacy item), and the most effective design of response scales, in order to maximise the validity and reliability of self-reports on the WHOQOL-ID; and to investigate further the impact of proxy responding. Additional research on the effect of social comparisons, not only between the public and adults with intellectual disabilities, but between different groups of ID clients themselves, may enhance understanding of the processes involved in making judgements about quality of life also.

Once the WHOQOL-ID is further refined, it would be useful to establish a definitive model for the instrument (requiring a much larger sample of ID adults); to explore the contribution of each domain to the prediction of the overall quality of life score (using multiple regression analysis); and to scrutinize the performance of the instrument within the context of different objective life conditions, to determine the normative range of subjective life quality on the scale and the related level of objective circumstances that might induce homeostatic defeat (Cummins, 1998, 2000).

Finally, a follow-up of the adults with intellectual disabilities who participated in the current study, using a within subjects design, would provide further useful insights into the properties of the WHOQOL-ID (e.g. longitudinal stability, test-retest reliability), as well as providing data on the longer term impact of community care for the community clients, and the sensitivity of the instrument to changes linked to the impact of resettlement of the hospital residents.

Bibliography

Ager, A. K., Annetts, S., Barlow, R., Copeland, C., Kemp, L., Sacco, C. and Richardson, S.A. (1988) Life Experiences and Quality of Life in the General Population: A Study of Leicester and its Environs Using the Life Experiences Checklist. *Mental Handicap Research Group Working Paper 2 (Revised)*, University of Leicester, Leicester.

Ager, A. K. (1988) Life Experiences and Quality of Life in the General Population: A Study of Undergraduate Students Using the Life Experiences Checklist. *Mental Handicap Research Group Working Paper 3*, University of Leicester, Leicester.

Ager, A. (1990) The *Life Experience Checklist*. NFER-Nelson, Windsor.

Ager, A. (1993) The Life Experiences Checklist Part 2: Applications in Service Evaluation and Quality Assurance. *Mental Handicap*, 21, 46-48.

Ager, A. (1998) *The BILD Life Experience Checklist.* BILD Publications, Kidderminster.

Ager, A. (1998) *The BILD Life Experience Checklist Manual.* BILD Publications, Kidderminster.

Ager, A. and Hatton, C. (1999) Discerning the Appropriate Role and Status of 'Quality of Life' for Persons with Intellectual Disability: A Reply to Cummins. *Journal of Applied Research in Intellectual Disabilities*, 12, 335-339.

Ager, A., Myers, F., Kerr, P., Myles, S. and Green, A. (2001) Moving Home: Social Integration for Adults with Intellectual Disabilities Resettling into Community Provision. *Journal of Applied Research in Intellectual Disabilities,* 14, 392-400.

Allen, D. (1990) Evaluation of a Community Based Day Service for People with Profound Mental Handicaps and Additional Special Needs. *Mental Handicap Research*, 3, 179-195.

Allen, R. and Schwarz, C (Eds.) (1998) *The Chambers Dictionary*. Chambers Harrap, Edinburgh.

Amir, M., Roziner, I., Knoll, A. and Neufeld, M.Y. (1999) Self-Efficacy and Social Support as Mediators in the Relation Between Disease Severity and Quality of Life in Patients with Epilepsy. *Epilepsia*, 40, 216-244.

Andresen, E.M. and Meyers, A.R. (2000) Health-Related Quality of Life Outcome Measures. *Archives of Physical Medicine and Rehabilitation*, 81, Suppl.2, 30-45.

Antaki, C and Rapley, M (1996) Questions and Answers to Psychological Assessment Schedules: Hidden Troubles in 'Quality of Life' Interviews. *Journal of Intellectual Disability Research*, 40, 421-437.

Asch, S.E. (1946) Forming Impressions of Personality. *Journal of Abnormal Social Psychology.* 41, 258-290.

Atkinson, D (1988) Research Interviews with People with Mental Handicaps. *Mental Handicap Research*, 1, 75-90.

Auburn, T.C. and Leach, S. (1989) An Evaluation of the Physical Environment of Two Community Based Homes for the Mentally Handicapped. *British Journal of Mental Subnormality*, 35, 83-93.

Baker, N. and Urquhart, J. (1987) *The Balance of Care for Adults with a Mental Handicap in Scotland.* ISD Publications, Edinburgh.

Bank-Mikkelson, N.E. (1969) A Metropolitan Area in Denmark: Copenhagen. In Kugel, R. and Wolfensberger, W. (Eds.) *Changing Patterns in Residential Services for the Mentally Retarded.* President's Committee on Mental Retardation, Washington DC.

Beecham, J., Knapp, M., McGilloway, S., Donelly, M., Kavanagh, S., Fenyo, A. and Mays, N. (1997) The Cost-Effectiveness of Community Care for Adults with Learning Disabilities Leaving Long-Stay Hospital in Northern Ireland. *Journal of Intellectual Disability Research*, 41, 30-41.

Bentler, P.M. and Wu, E.J.C. (1995) *EQS for Windows Users Guide.* Multivariate Software Inc, Encino, CA.

Blunden, R. (1975) *A Large Scale Epidemiological Study of Mental Handicap: Uses and Limitations.* IASSMD, The Hague.

Bonomi, A.E., Patrick, D.L., Bushnell, D.M. and Martin, M. (2000) Validation of the United States' Version of the World Health Organisation Quality of Life (WHOQOL) Instrument. *Journal of Clinical Epidemiology*, 53, 1-12.

Booth, W., Booth, T. and Simons, K. (1990) Return Journey: The Relocation of Adults from Long Stay Hospital into Hostel Accommodation. *British Journal of Mental Subnormality*, 36, 87-97.

Borthwick-Duffy, S.A. (1989) Quality of Life: The Residential Environment. In Kiernan, W.E. & Schalock, R.L. (Eds.) *Economics, Industry and Disability: A Look Ahead.* Brookes, Baltimore.

Borthwick-Duffy S.A. (1992) Quality of Life and Quality of Care in Mental Retardation. In Rowitz, L. (Ed.), *Mental Retardation in the Year 2000.* Springer-Verlag, Berlin.

Bowley, C. and Kerr, M. (2000) Epilepsy and Intellectual Disability. Journal of Intellectual Disability Research, 44, 529-543.

Bowling, A (1997a) *Research Methods in Health: Investigating Health and Health Services.* Open University Press, Buckingham.

Bowling, A (1997b) *Measuring Health: A Review of Quality of Life Measurement Scales* (2nd Edition). Open University Press, Buckingham.

Bullinger, M., Power, M.J., Aaronson, N.K., Cella, D.F. and Anderson, R.T. (1996) Creating and Evaluating Cross-Cultural Instruments. In Spilker, B. (Ed.) *Quality of Life and Pharmaco-economics in Clinical Trials* (2nd Edition). Lippincott-Raven, Philadelphia.

Braddock, D., Emerson, E., Felce, D. and Stancliffe, R.J. (2001) Living Circumstances of Children and Adults with Mental Retardation or Developmental Disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews.* 7, 115-121.

Bradley, V. (1996) Foreword. In Mansell, J. and Ericsson, K. (Eds.) *De-institutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA.* Chapman Hall, London.

Bratt, A. and Johnston, R. (1988) Changes in Lifestyle for Young Adults with Profound Handicaps Following Discharge from Hospital Care to a 'Second Generation' Housing Project. *Mental Handicap Research*, 1, 49-74.

Bratt, A. and Kirby. R. (1995) Home and Away. *Health Service Journal*, 32-33.

Brown, I., Renwick, R., and Nagler, M. (1996) The Centrality of Quality of Life in Health Promotion and Rehabilitation. In Renwick, R, Brown, I. and Nagler, M. (Eds.) *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues and Applications*. Sage Publications, Thousand Oaks.

Browne, R.A., Gunzburg, H.C., Johnston-Hannah, L.G.W., McColl, K., Oliver, B. and Thomas, A. (1971) Symposium on the 'Hospitalised' Patient in the Community: I The Needs of Patients in Subnormality Hospitals if Discharged to Community Care. *British Journal of Mental Subnormality*, 17, 1-18.

Bruininks, R.H. (1990) There is More to Service Change than Just a Zip Code. *American Journal on Mental Retardation*, 95, 13-15.

Bryant, F.B and Yarnold, P.R. (1998) Principal-Components Analysis and Exploratory and Confirmatory Factor Analysis. In Grimm, L.G. and Yarnold, P.R. (Eds.) *Reading and Understanding Multivariate Statistics.* American Psychological Association, Washington D.C.

Cadell, J. and Woods, P.A. (1984) The Bryn-y-Neuadd Degree of Dependency Rating Scale; An Extension of the Wessex mental Handicap Register. *Mental Handicap*, 12, 142-145.

Cambridge, P., Hayes, L. and Knapp, M. (1994) *Care in the Community: Five Years On.* Ashgate, Aldershott.

Campaign for the Mentally Handicapped (1970) *Future Services for the Mentally Handicapped: A Manifesto*. CMH, London.

Campaign for the Mentally Handicapped (1972) *Even Better Services for the Mentally Handicapped*. CMH, London.

Campaign for the Mentally Handicapped (1984) *Key Concepts in Community Based Services.* CMH, London

Campbell, A. and Rodgers, W.L. (1972) *The Human Meaning of Social Change*. Russell Sage, New York. Cited in Renwick, R., Brown, I. and Nagler, M. (Eds.) (1996) *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues and Applications*. Sage Publications, Thousand Oaks.

Cattermole, M., Jahoda, A. and Markova, I. (1988) Leaving Home: The Experience of People with a Mental Handicap. *Journal of Mental Deficiency Research*, 32, 47-57.

Cattermole, M., Jahoda, A. and Markova, I. (1988) Life in a Mental Handicap Hospital: The View from the Inside. *Mental Handicap*, 16, 136-139.

Clare, I.C. H. and Murphy, G.H. (1993) MIETS: A Service Option for People with Mild Mental Handicaps and Challenging Behaviour and/or Psychiatric Problems. *Mental Handicap Research*, 6, 70-91.

Clark, A.D.B. and Clark, A.M. (1953) How Constant is the IQ? *The Lancet,* 2, 877.

Clark, A.D.B. and Clark, A.M. (1954) Cognitive Changes in the Feeble-minded. *British Journal of Psychology,* 45, 173-179.

Clark, A.D.B., Clark, A.M. and Reinman, S. (1958) Cognitive and Social Changes in the Feeble-minded: Three further Studies. *British Journal of Psychology*, 49, 144-157.

Clark, A.M. and Hermelin, B.F. (1955) Adult Imbeciles, Their Abilities and Trainability. *The Lancet*, 2, 337-339.

Clark-Carter, D. (1997) *Doing Quantitative Psychological Research: From Design to Report.* Psychology Press, Hove.

Clegg, J. and Standen, P.J. (1991) Friendship Among Adults Who Have Developmental Disabilities. *American Journal on Mental Retardation*, 95, 663-671.

Conneally, S., Boyle, G. and Smyth, F. (1992) An Evaluation of the Use of Small Group Homes for Adults with Severe and Profound Mental Handicap. *Mental Handicap Research*, 5, 146-168.

Cortazzi, D. (1969) The Bottom of the Barrel. *British Journal of Metal Subnormality*, 15, 1.

Cragg, R. and Harrison, J. (1984) *Living in a Supervised Home: A Questionnaire on Quality of Life.* West Midlands Campaign for People with Mental Handicap, Kidderminster.

Cullen, C., Whoriskey, M. Mackenzie, K., Mitchell, W., Ralston, K., Shreeve, S. and Stanley, A. (1995) The Effects of De-institutionalisation on Adults with Learning Disabilities. *Journal of Intellectual Disabilities Research*, 39, 484-494.

Cummins, R.A. (1991) The Comprehensive Quality of Life Scale – Intellectual Disability: An Instrument Under Development. *Australian and New Zealand Journal of Developmental Disabilities*, 17, 259-264.

Cummins, R.A. (1994) The Comprehensive Quality of Life Scale (ComQol): Instrument Development and Psychometric Evaluation on College Staff and Students. *Educational and Psychological Measurement*, 54, 372-382.

Cummins, R.A. (1997a) Self-rated Quality of Life Scales for People with an Intellectual Disability: A Review. *Journal of Applied Research in Intellectual Disabilities* 10, 199-216.

Cummins, R.A. (1997b) An Initial Evaluation of the Comprehensive Quality of Life Scale – Intellectual Disability. *International Journal of Disability, Development and Education*, 44, 7-19.

Cummins, R.A. (1998) The Second Approximation to an Internal Standard for Life Satisfaction. *Social Indicators Research*, 43, 307-334.

Cummins, R.A. (2000) Objective and Subjective Quality of Life: An Interactive Model. *Social Indicators Research*, 52, 55-72.

Cummins, R.A. (2001a) Living with Support in the Community: Predictors of Satisfaction with Life. *Mental Retardation and Developmental Disabilities*, 7, 99-104.

Cummins, R.A. (2001b) Self-Rated Quality of Life Scales for People with an Intellectual Disability: A Reply to Ager and Hatton. *Journal of Applied Research in Intellectual Disabilities,* 14, 1-11.

Cummins, R.A. (2002) The Validity and Utility of Subjective Quality of Life: A Reply to Hatton and Ager. *Journal of Applied Research In Intellectual Disabilities*, 15, 261-268.

Dagnan, D, Jones, J. and Ruddick, L. (1994) The Psychometric Properties of a Scale for assessing Quality of Life of People with Learning Disabilities in Residential Care. *British Journal of Developmental Disabilities*, 40, 98-103.

Dagnan, D., Look, R., Ruddick, L. and Jones, J. (1995) Changes in the Quality of Life of People with Learning Disabilities Who Move from Hospital to Live in Community Based Homes. *International Journal of Rehabilitation Research*, 18, 115-122.

Dagnan, D. and Ruddick, L. (1995) The Use of Analogue Scales and Personal Questionnaires for Interviewing People with Learning Disabilities. *Clinical Psychology Forum*, 79, 21-24.

Dagnan, D., Ruddick, L. and Jones, J. (1998) A Longitudinal Study of the Quality of Life of Older People with Intellectual Disability After leaving Hospital. *Journal of Intellectual Disability Research*, 42, 112-121.

Dalgleish, M. and Mathews, R. (1981) Some Effects of Staffing Levels and Group Size of the Quality of Day Care for Severely Mentally Handicapped Adults. *British Journal of Mental Subnormality,* 27, 30-35.

Day, H. and Jankey, S.G. Lessons from the Literature: Towards a Holistic Model of Quality of Life. In Renwick, R, Brown, I. and Nagler, M. (Eds.) *Quality of Life in Health Promotion and Rehabilitation*: *Conceptual Approaches, Issues and Applications*. Sage Publications, Thousand Oaks.

Department of Health and Social Security (1971) *Better Services for the Mentally Handicapped.* (Cmnd 4683) HMSO, London.

Department of Health and Social Security (1989) *Caring for People: Community Care in the Next Decade and Beyond.* (Cmnd 849) HMSO, London.

Davies, B and Challis, D. (1986) *Matching Resources to Needs in Community Care.* Gower Publishing Company, Aldershott.

Davies, L. (1988) Community Care: The Costs and Quality. *Health Services Management Research,* 1, 145-155.

Davies, L., Felce, D., Lowe, K. and de Paiva, S. (1991) The Evaluation of NIMROD, a Community Based Service for People with Mental Handicap: Revenue Costs. *Health Services Management Research*, 4, 170-180.

de Kock, U., Saxby, H., Thomas,M. and Felce, D. (1988) Community and Family Contact: An Evaluation of Small Community Homes for Adults with Severe and Profound Mental Handicaps. *Mental Handicap Research*, 1, 127-140.

De Vries, J. and Van Heck, G.L. (1997) The World Health Organisation Quality of Life Assessment Instrument (WHOQOL-100): Validation Study with the Dutch Version. *European Journal of Psychological Assessment*, 13, 164-178.

Digby, A. (1996) Contexts and Perspectives. In Wright, D. and Digby, A. (Eds.) *From Idiocy to Mental Deficiency: Historical Perspectives on People with Learning Disabilities.* Routledge, London.

Dockrell, J. Gaskell, G., Rehman, H and Normand, C. (1993) Service Provision for People with Mild Learning Difficulty and Challenging Behaviours: The MIETS Evaluation. In Kiernon, C. (Ed.) *Research to Practice?* BILD, Clevedon.

Donegan, C. and Potts, M. (1988) People with Mental Handicap Living Alone in the Community: A Pilot Study of their Quality of Life. *British Journal of Mental Subnormality*, 34, 10-22.

Donnelly, M., McGilloway, S., Mays, Knapp, M., Kavanagh, S. Beecham, J. and Fenyo, A. (1996) One and two Year Outcome for Adults with Learning Disabilities Discharged to the Community. British Journal of Psychiatry, 168, 598-606.

Donnelly, M., McGilloway, S., Mays, N., Perry, S. and Lavery, C. (1997) A Three to Six Year Follow Up of Former Long Stay Residents of Mental Handicap Hospitals in Northern Ireland. *British Journal of Clinical Psychology*, 36, 585-600.

Dugdale, R.L. (1910) *The Jukes: A study in crime, disease and heredity 1877.* Putnam, London. Cited in: Jones, K. (1960) *Mental Health and Social Policy 1845-1959.* Routledge and Kegan Paul, London.

Duvdevany, I. (2002) Self-Concept and Adaptive Behaviour of People with Intellectual Disability in Integrated and Segregated Recreation Activities. *Journal of Intellectual Disability Research,* 46, 419-429.

Emerson, E. (1985) Evaluating the Impact of De-institutionalisation Research on the Lives of Mentally Retarded People. *American Journal on Mental Deficiency*, 90, 277-288.

Ericsson, K. and Mansell, J. (1996) Introduction: Towards De-institutionalisation. In Mansell, J. and Ericsson, K. (Eds.) *De-institutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA.* Chapman Hall, London.

Emerson, E. (2001) *Challenging Behaviour: Analysis and Intervention in People with Intellectual Disabilities* (2nd Edition). Cambridge University Press, New York.

Emerson, E. and Hatton, C. (1994) *Moving Out: Relocation from Hospital to Community.* HMSO, London.

Emerson, E. and Hatton, C. (1996) Impact of De-institutionalisation on Service Users in Britain. In Mansell, J. and Ericsson, K. (Eds.) *De-institutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA.* Chapman Hall, London.

Emerson, E. and Hatton, C. (1996) De-institutionalisation in the UK and Ireland: Outcomes for Service Uses. *Journal of Intellectual and Developmental Disability*, 21, 17-37.

Emerson, E., Beasley, F., Offord, G. and Mansell, J. (1992) Specialised Housing for People with Seriously Challenging Behaviours. *Journal of Mental Deficiency Research*, 36, 291-307.

Emerson, E., Hatton, C., Felce, D. and Murphy, G. (2001) *Learning Disabilities - The Fundamental Facts.* The Mental Health Foundation, London.

Emerson, E., McGill, P. and Mansell, J. (1994) *Severe Learning Disabilities and Challenging Behaviours; Designing High Quality Services.* Chapman and Hall, London.

Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Hatton, C., Hallam, A., Knapp, M., Järbrink, K., Netten, A. and Linehan, C. (2000) The Quality and Costs of Community Based Residential Supports and Residential Campuses for people with Severe and Complex Disabilities. *Journal of Intellectual and Developmental Disability*, 25, 263-279.

Eser, E., Fidaner, H., Eser, S.Y., Fidaner, C. and Elbi, H. (2000) Derivation of Response Scales for WHOQOL TR: The Effect of the Level of Education on the Use of Visual Analogue Scales. *European Psychologist*, 5, 278-284.

Fallowfield, L. (1990) *The Quality of Life: The Missing Measurement in Health Care*. Souvenir Press, London.

Farmer, R., Holroyd, S. and Rhode, J. (1990) Differences in Disability Between People with Mental Handicaps Who Were Resettled in the Community and Those Who Remained in Hospital. *British Medical Journal*, 301, 646.

Farquhar, M. (1995) Elderly People's Definitions of Quality of Life. *Social Science and Medicine*, 41, 1439-1446.

Felce, D. (1981) The Capital Costs of Alternative Residential Facilities for Mentally Handicapped People. *British Journal of Psychiatry*, 139, 230-237.

Felce, D. (1989) *The Andover Project: Staffed Housing for Adults with Severe or Profound Mental Handicaps*. British Institute of Mental Handicap, Kidderminster.

Felce, D. (1996) Quality of Support for Ordinary Living. In Mansell, J. and Ericsson, K. (Eds.) *De-institutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA*. Chapman Hall, London

Felce, D. (1997) Defining and Applying the Concept of Quality of Life. *Journal of Intellectual Disability Research* 41, 126-135.

Felce, D., de Kock, U. and Repp, A. (1986) An Eco-behavioural Analysis of Small Community Based Houses and Traditional Large Hospitals for Severely and Profoundly Mentally Handicapped Adults. *Applied Research in Mental Retardation*, 7, 393-408.

Felce, D. and Emerson, E. (2000) Observational Methods in Assessment of Quality of Life. In Thompson, T., Felce, D. and Symons, F.J. (Eds.) *Behavioural Observation: Technology and Applications in Developmental Disabilities*. Paul H. Brookes Publishing Company, Baltimore.

Felce, D., Kushlick, A. and Smith, J. (1980) An overview of the research on alternative residential facilities for the severely mentally handicapped in Wessex. *Advances in Behaviour Research and Therapy*, 3, 1-4.

Felce, D., Lowe, K. and de Paiva, S. (1994) Ordinary Housing for People with Severe Learning Disabilities and Challenging Behaviours. In Emerson, E., McGill, P. and Mansell, J. (Eds.) *Severe Learning Disabilities and Challenging Behaviours; Designing High Quality Services*. Chapman and Hall, London.

Felce, D. and Perry, J. (1995a) The Extent of Support for Ordinary Living Provided in Staffed Housing: The Relationship Between Staffing Levels, Resident Characteristics, Staff-Resident Interactions and Resident Activity Patterns. *Social Science and Medicine*, 40, 799-810.

Felce, D. and Perry, J. (1995b) Quality of Life: Its Definition and Measurement. *Research in Developmental Disabilities* 16, 51-74.

Felce, D. and Perry, J. (1996) Exploring Current Conceptions of Quality of Life. In Renwick, R, Brown, I. and Nagler, M. (Eds.) *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues and Applications*. Sage Publications, Thousand Oaks.

Felce, D. and Perry, J. (1997) A PASS 3 Evaluation of Community Residences in Wales. *Mental Retardation*, 35, 170-176.

Felce, D. and Repp, A. (1992) The Behavioural and Social Ecology of Community Houses. *Research in Developmental Disabilities*, 13, 27-42.

Felce, D., Repp, A., Thomas, M., Ager, A. and Blunden, R. (1991) The Relationship of Staff: Client Ratios, Interactions, and Residential Placement. *Research in Developmental Disabilities*, 12, 315-331.

Felce, D., Thomas, M., de Kock, U., Saxby, H. and Repp, A. (1985) An Ecological Comparison of Small Community Based Houses and Traditional Institutions: Physical Setting and the Use of Opportunities. *Behaviour Research and Therapy*, 23, 337-348.

Felce, D. and Toogood, S. (1988) *Close to Home*. BIMH, Kidderminster.

Fernando, L., Cresswell, J. and Barakat, F. (2001) Study of Physical Health Needs of People with Learning Disabilities Living in the Community. *British Journal of Developmental Disabilities*, 47, 31-37.

Festinger, L. (1954) A Theory of Social Comparison Processes. *Human Relations*, 7, 117-140.

Firth, H. and Rapley, M. (1990) From *Acquaintanceship for Friendship: Issues for People with Learning Disabilities*. BIMH Publications, Kidderminster.

Fleming, I. and Stenfert Kroese, B. (1990) Evaluation of a Community Care Project for People with Learning Difficulties. *Journal of Mental Deficiency Research*, 34, 451-464.

Flectcher, A.E., Dickinson. E.J. and Philp, I. (1992) Review: Audit Measures: Quality of Life Instruments for Everyday Use with Elderly Patients. *Age and Ageing*, 21, 142-150.

Flynn, M. (1989) *Independent Living for Adults with Mental Handicap: 'A Place of My Own'*, Cassell Educational, London.

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M. and Beecham, J. (2002) The Quality of Life of People 12 Years after Resettlement from Long Stay Hospitals: User's Views on their Living Environment, Daily Activities and Future Aspirations. *Disability and Society*, 17, 741-758.

Garratt, A., Schmidt, L., Mackintosh, A. and Fitzpatrick, R. (2002) Quality of Life Measurement: Bibliographic Study of Patient Assessed Health Outcome Measures. *British Medical Journal*, 324, 1417-1419.

Gerson, E.H. (1976) On 'Quality of Life'. *American Sociological Review*, 41, 793-806.

Goddard, H.H. (1912) *The Kallikak Family: A study in the heredity of feeble-mindedness*. McMillan, New York. Cited in: Jones, K. (1960) *Mental Health and Social Policy 1845-1959*. Routledge and Kegan Paul, London.

Goddard, H.H. (1914) What it Means. In Rosen, M., Clark, G.R., and Kivitz, M.S. (1976) *The History of Mental Retardation: Collected Papers* (Volume 2). University Park Press, Baltimore.

Goffman, E. (1961) Asylum: *Essays on the Social Situation of Mental Patients and Other Inmates*. Doubleday, New York.

Goffman, E. (1970) *Asylums*. Penguin, Harmondsworth, England.

Goode, D.A. and Hogg, J. (1994) Towards an Understanding of Holistic Quality of Life in Persons with Profound Intellectual and Multiple Disabilities. In Goode, D. (Ed.) *Quality of Life for Persons with Disabilities: International Perspectives and Issues*. Brookline, Cambridge, MA.

Griffiths, R. *Community Care: Agenda for Action*. HMSO, London.

Grimm, L.G. and Yarnold, P.R. (1998) *Reading and Understanding Multivariate Statistics*. American Psychological Association, Washington D.C.

Gullone, E. and Cummins, R.A. (1999) The Comprehensive Quality of Life Scale: A Psychometric Evaluation with an Adolescent Sample. *Behaviour Change*, 16, 127-139.

Gunzburg, H.C. (1960) *Social Rehabilitation of the Subnormal*. Balliere, Tindall and Cox, London.

Gunzburg, H.C. (1961) The Case for Comprehensive Training. British Journal of Mental Subnormality, 7, 53.

Gunzburg, H.C. (1968) *Social Competence and Mental Handicap*. Balliere, Tindall and Cassell, London.

Gunzburg, H.C. and Gunzburg, A. L. (1973) *Mental Handicap and Physical Environment*. Balliere Tindall, London.

Haas, B.K. (1999) Clarification and Integration of Similar Quality of Life Concepts. *Journal of Nursing Scholarship*, 31, 215-220.

Hagerty, M.R., Cummins, R.A., Ferriss, A.L., Land, K., Michalos, A.C., Peterson, M., Sharpe, A., Sirgy, J. and Vogel, J. (2001) Quality of Life Indexes for National Policy: Review and Agenda for Research. *Social Indicators Research*, 55, 1-96.

Hair, J.F., Anderson, R.E., Tatham, R.L. and Black, W.C. (1998) *Multivariate data Analysis* (5th Edition). Prentice Hall, New Jersey.

Hattersley, J., Hosking, G.P., Morrow, D. and Myers, M. (1987) *People with Mental Handicaps: perspectives on Intellectual Disability*. Faber and Faber, London.

Hatton, C. (1998) Whose Quality of Life is it Anyway? Some Problems with the Emerging Quality of Life Consensus. *Mental Retardation*, 36, 104-115.

Hatton, C., Emerson, E., Robertson, J., Henderson, D. and Cooper, J. (1995) The Quality and Costs of Residential Services for Adults with Multiple Disabilities: A Comparative Evaluation. *Research in Developmental Disabilities*, 16, 439-460.

Heal, L.W., Sigelman, C.K. and Switzky, H.N. (1978) Research on Community Residential Alternatives for the Mentally Retarded. In Ellis, N.R. (Ed.) *International Review of Research in Mental Retardation*. Academic Press, New York.

Helm, D.T. (2000) The Measurement of Happiness. *American Journal on Mental Retardation*, 105, 326-335.

Hemming, H., Lavender, T. and Pill, R. (1981) Quality of Life of Mentally Retarded Adults Transferred from Large Institutions to New Small Units. *American Journal of Mental Deficiency, 86, 157-169.*

Hensel, E., Rose, J., Sternfert-Kroese, B. and Banks-Smith, J. (2002) Subjective Judgements of Quality of Life: A Comparison Study Between People with Intellectual Disability and Those without Disability. *Journal of Intellectual Disability Research*, 46, 95-107.

Hogg, J, Lucchino, R., Wang, K., Janicki, M (2000) *Healthy Aging – Adults with Intellectual Disabilities: Aging and Social Policy.* World Health Organisation, Geneva.

Holland, A. and Meddis, R. (1993) People Living in Community Homes: The Influences on Their Activities. *Mental Handicap Research*, 6, 333-345.

Holland, A.J. (2000) Ageing and Learning Disability. *British Journal of Psychiatry*, 176, 26-31.

Howells, G. (1986) Are the medical Needs of Mentally Handicapped Adults Being Met? *Journal of the Royal College of General Practitioners*, 36, 449-453.

Hughes, C., Hwang, B., Kim, J.H., Eisenman, L.T. and Killian, D.J. (1995) Quality of Life in Applied Research: A Review and Analysis of Empirical Measures. *American Journal on Retardation,* 99, 623-641.

Hutton, G. (2000) *The Royal Scottish National Hospital: 140 Years*. Forth Valley Primary Care NHS Trust, Larbert.

IASSID (2000) *Quality of Life: It's Conceptualisation, Measurement and Application. A Consensus Document.*

Jahoda, A., Cattermole, M. and Markova, I. (1990) Moving Out: An Opportunity for Friendship and Broadening Social Horizons? Journal of Mental Deficiency Research, 34, 127-139.

Janssen, C.G.C. and Vreeke, G.J. (1995) Outcome Indicators in the Care for People with a Mental Handicap. *British Journal of Developmental Disabilities*, 41, 79-89.

Janssen, C.G.C., Vreeke, G.J., Resnick, S. and Stolk, J. (1999) Quality of Life of People with Mental Retardation – Residential Versus Community Living. *British Journal of Developmental Disabilities,* 45, 3-15.

Jirojanakul, P. and Skevington, S. (2000) Developing a Quality of Life Measure for Children aged 5-8 Years. *British Journal of Health Psychology*, 5, 299-321.

Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D. and Pagler, J. Opportunity and the Promotion of Activity among Adults with Severe Intellectual Disability Living in the Community: The Impact of Staff Training in Active Support. *Journal of Intellectual Disabilities Research*, 43, 164-178.

Jones, J., Dagnan, D. and Ruddick, L. (1997) A Pilot Study of the use of the SF-36 to Assess Health Status of Adults with learning Disabilities Living in Small Homes. *British Journal of Developmental Disabilities*, 43, 27-35.

Jones, K. (1960) *Mental Health and Social Policy 1845-1959*. Routledge and Kegan Paul, London.

Jones, K. (1972) *A History of the Mental Health Services*. Routledge and Kegan Paul, London.

Jones, K. (1975) Opening the Door: *A Study of New Policies for the Mentally Handicapped*. Routledge and Kegan Paul, London

Kerr, M, Fraser, W and Felce, D (1996) Primary Health Care for People with a Learning Disability: A Keynote Review. *British Journal of Learning Disabilities*, 24, 2-8.

Kind, P. (1988) *The Design and Construction of Quality of Life Measures*. Discussion Paper 43. Centre for Health Economics, University of York, York.

King, R.D. and Raynes, N.V. (1968) An Operational Measure of Inmate Management in Residential Institutions, *Social Science and Medicine*, 2, 41-53.

King, R.D., Raynes, N.V. and Tizard, J. (1971) *Patterns of Residential Care: Sociological Studies of Institutions for Handicapped Children*. Routledge and Kegan Paul, London.

King's Fund (1980) *An Ordinary Life: Comprehensive Locally-based Residential Services for Mentally Handicapped People*. King's Fund Centre, London.

Kishi, G., Teelucksingh, B., Zollers, N., Park-Lee, S. and Meyer, L. (1988) Daily Decision Making in Community Residences: A Social Comparison of Adults With and Without Mental Retardation. American Journal of Mental Deficiency, 92, 430-435.

Kitzinger, J. and Barbour, R.S. (1999) Introduction: the Challenge of Focus Groups. In Barbour, R.S. and Kitzinger, J. (Eds.) *Developing Focus Group Research: Politics, Theory and Practice*. Sage Publications, London.

Kleinberg, J. and Galligan, B. (1993) Effects of De-institutionalisation on Adaptive Behaviour of Mentally Retarded Adults. *American Journal of Mental Deficiency*, 88, 21-27.

Kline, P. (1983) *Personality: Measurement and Theory*. Hutchison, London.

Kline, P. (1993) *The Handbook of Psychological Testing*. Routledge, London.

Kline, P. (1994) *An Easy Guide to Factor Analysis*. Routledge, London.

Knapp, M., Cambridge, P., Thomason, C., Beecham, J., Allen, C. and Darton, R. (1992) *Care in the Community: Challenge and Demonstration*. Ashgate, Aldersott.

Knox, M. and Hickson, F. (2001) The Meanings of Close Friendship: the Views of Four People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14, 276-291.

Koch, T. (2000) Life Quality vs the 'Quality of Life': The Assumptions Underlying Prospective Quality of Life Instruments in Health Care Planning. *Social Science and Medicine*, 51, 419-427.

Kong, I.L.L. and Molassiotis, A. (1999) Quality of Life, Coping and Concerns in Chinese Patients After Renal Transplant. *International Journal of Nursing Studies*, 36, 313-322.

Korman, N. and Glennerster, H. (1985) *Closing a Hospital: The Darenth Park Project*. Bedford Square Press, London.

Kushlick, A. (1968) Residential Care for the Mentally Retarded. *International League of Societies for the Mentally Handicapped, Fourth International Congress*. Jerusalem, 1968.

Kushlick, A. and Cox, G.R. (1967) The Ascertained Prevalence of mental Subnormality in the Wessex Region on 1st July 1963. *Proceedings of the First Congress of the International Association for the Scientific Study of Mental Deficiency*. Montpellier, 1967

Kushlick, A., Blunden, R. and Cox, G. (1973) A Method of Rating Behaviour Characteristics for Use in Large Scale Surveys of Mental Handicap. *Psychological Medicine*, 3, 466-478.

Krueger, R.A. (1994) *Focus Groups: A Practical Guide for Applied Research* (2nd Edition). Sage Publications, Thousand Oaks.

Krueger, R.A. (1996) Group Dynamics and Focus Groups. In Spilker, B. (Ed.) *Quality of Life and Pharmacoeconomics in Clinical Trials* (2nd Edition). Lippincott-Raven, Philadelphia.

Landesman-Dwyer, S. (1981) Living in the Community. *American Journal of Mental Deficiency*, 86, 223-234.

Leck, I, Gordon, W.L. and McKeown, T. (1967) Medical and Social Needs of Patients in Hospitals for the Mentally Subnormal. *British Journal of Preventive and Social Medicine*, 21, 115-121.

Locker, D., Rao, B. and Weddell, J.M. (1984) Evaluating Community Care for the Mentally Handicapped Adult: A Comparison of Hostel, Home and Hospital Care. *Journal of Mental Deficiency Research*, 28, 189-198.

Look, R. J. (1987) *The Quality of Life of Mentally Handicapped People: Assessment of Life Experiences Within a Range of Institutional and Community Settings*. Unpublished Masters Dissertation, University of Birmingham, Birmingham.

Lowe, K. and de Paiva, S. (1990) *The Evaluation of NIMROD, a Community Based Service for People with Mental Handicap*. Mental Handicap in Wales Applied Research Unit, Cardiff.

Lowe, K. and de Paiva, S. (1991) *NIMROD: An Overview*. HMSO, London.

Lowe, K., de Paiva, S. and Felce, D. (1993) Effects of a Community Based Service on Adaptive and Maladaptive Behaviours: A Longitudinal Study. *Journal of Intellectual Disability Research,* 37, 3-22.

Lundsky, Y. and Benson, B.A. (2001) Association between Perceived Social Support and Strain, and Positive and Negative Outcomes for Adults with Mild Intellectual Disability. *Journal of Intellectual Disability Research*, 45, 106-114.

Maes, B., Geervaert, L. and Van del Bruel, B. (2000) Developing a Model for Quality Evaluation in Residential Care for People with Intellectual Disability. *Journal of Intellectual Disability Research,* 44, 544-552.

Maisto, A.A. and Hughes, E. Adaptation to Group Home Living for Adults with Mental Retardation as a Function of Previous Residential Placement. *Journal of Intellectual Disability Research*, 39, 15-18.

Malin, N. A. (1982) Group Homes for Mentally Handicapped Adults: Residents' Views on Contact and Support. *British Journal of Mental Subnormality*, 28, 29-34.

Malin, N., Race, D. and Jones, G. (1980) *Services for the Mentally Handicapped in Britain*. Croom Helm, London.

Mansell, J. and Beasley, F. (1990) Evaluating the Transfer to Community Care. In Fraser, W.I. (Ed.) *Key Issues in Mental Retardation Research*, Routledge, London.

Mansell, J. and Beasley, F. (1993) Small Staffed Houses for People with Severe Learning Disabilities and Challenging Behaviours. *British Journal of Social Work*, 23, 329-344.

Mansell, J. and Ericsson, K. (Eds.) (1996) *De-institutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA*. Chapman Hall, London

Mansell, J., Felce, D., Jenkins, J. and de Kock, U. (1982) Increasing Staff Ratios in an Activity with Severely Mentally Handicapped People. *British Journal of Mental Subnormality*, 28, 97-99.

Mansell, J., Felce, D., Jenkins, J., de Kock, U. and Toogood, S. (1987) *Developing Staffed Housing for People with Mental Handicaps*. Costello, Tunbridge Wells.

Martin, J.P. (1984) *Hospitals in Trouble*. Basil Blackwell, Oxford.

Martindale, A. (1976) A Case Register on an Information System in a Development Project for the Mentally Handicapped. *British Journal of Mental Subnormality*, 1976, 12, 70-76.

Martindale, A. and Kilby, C.A. (1982) Closure of an Old Mental Handicap Hospital and the Short Term and Long Term Effects on Residents. *British Journal of Mental Subnormality*, 28, 3-12.

McConkey, R., Naughton, M. and Nugent, U. (1983) Have We Met? Community Contacts of Adults Who Are Mentally Handicapped. *Mental Handicap*, 11, 57-59.

McConkey, R., Walsh, P.N. and Conneally, S. (1993) Neighbours' Reactions to Community Services: Contrasts Before and After Services Open in Their Locality. *Mental Handicap Research*, 6, 131-141.

McGill, P, Emerson, E. and Mansell, J. (1994) Individually Designed Residential Provision for People with Seriously Challenging Behaviours. In Emerson, E., McGill, P. and Mansell, J. (Eds.) *Severe Learning Disabilities and Challenging Behaviours; Designing High Quality Services*. Chapman and Hall, London.

McHatton, M., Collins, G. and Brooks, E. (1988) Evaluation in Practice: Moving from a 'Problem' Ward to a Staffed Flat. *Mental Handicap Research*, 1, 141-151.

McKeown, T. and Teruel, J.R. (1970) An Assessment of the Feasibility of Discharge of Patients in Hospitals for the Subnormal. *British Journal of Preventive Medicine*, 24, 116-119.

McLaren, J. and Bryson, S.E. (1987) Review of Recent Epidemiological Studies of Mental Retardation: Prevalence, Associated Disorders and Etiology. *American Journal of Mental Retardation*, 92, 243-254.

McVilly, K.R., Burton-Smith, R.M. and Davidson, J.A. (2000) Concurrence Between Subject and Proxy Ratings of Quality of Life for People With and Without Intellectual Disabilities. *Journal of Intellectual and Developmental Disability*, 25, 19-39.

Mental Welfare Commission for Scotland (1985) Report for 1985. HMSO, Edinburgh.

Mental Welfare Commission for Scotland (1986) Report for 1986. HMSO, Edinburgh.

Michie, A.M., Lindsay, W.R., Smith, A.H.W. and Todman, J. (1997) A Controlled Investigation of Changes Following a Programme of Community Living Skills Training and the Validation of These Changes Through Relocation. *Health Bulletin*, 55, 185-196.

Morgan, D.L. (1997) *Focus Groups as Qualitative Research* (2nd Edition). Sage Publications, California.

Morgan, D.L. and Krueger, R.A. (1993) When to Use Focus Groups and Why. In Morgan, D.L. (Ed.) *Successful Focus Groups: Advancing the State of the Art.* Sage Publications, California.

Morris, P. (1969) *Put Away: A Sociological Study of Institutions for the Mentally Retarded.* Routledge and Kegan Paul, London

Murphy, G. and Clare, I. (1991) MIETS: A Service Option for People with Mild Mental Handicaps and Challenging Behaviour or Psychiatric Problems: 2 Assessment, Treatment and Outcome for Service Users and Service Effectiveness. *Mental Handicap Research*, 4, 180-206.

Murphy, G.H., Estien, D. and Clare, I.C.H. (1996) Services for People with Mild Intellectual Disabilities and Challenging Behaviour: Service Users Views. *Journal of Applied Research in Intellectual Disabilities*, 9, 256-283.

Myers, C.E. and Clacher, J. (1987) Historical Determinants of Residential Care. In Landsman, S. and Vietze, P (Eds.) *Living Environments and Mental Retardation.* American Association on Mental Retardation, Washington.

Myers, F., Ager, A., Green, A.M., Kerr, P., Myles, S., and Matheson, J. (1997) *Moving Home: Community Integration and Costs Associated with Varying Forms of Provision for Adults with Learning Disabilities.* Unpublished Report to Edinburgh Healthcare NHS Trust.

National Development Group (1978) *Helping Mentally Handicapped People in Hospital.* DHSS, London.

Nirje, B. (1970) The Normalisation Principle – Implications and Comments. *Journal of Mental Subnormality*, 16, 62-70.

Nirje, B. (1976) The Normalisation Principle. In Kugel, R. and Shearer, A. (Eds.) *Changing Patterns in Residential Services for the Mentally Retarded.* President's Committee on Mental Retardation, Washington DC.

O' Brien, J. (1987) A Guide to Life-Style Planning: Using the Activities Catalog to Integrate Services and Natural Support Systems. In Wilcox, B. and Bellamy, T. (Eds.) *A Comprehensive Guide to the Activities Catalog: An Alternative Curriculum for Youth and Adults with Severe Disabilities.* Paul Brookes Publishing Co., Baltimore.

O'Brien, J. and Tyne, A. (1981) *The Principle of Normalisation in Human Services.* National Institute on Mental Retardation, Toronto.

O'Carroll, R.E., Cossar, J.A., Couston, M.C. and Hayes, P.C. (2000a) Sensitivity to Change Following Liver Transplantation: A Comparison of Three Instruments that Measure Quality of Life. *Journal of Health Psychology*, 5, 69-74.

O'Carroll, R.E., Smith, K., Couston. M., Cossar, J.A. and Hayes, P.C. (2000b) A Comparison of the WHOQOL-100 and the WHOQOL-BREF in Detecting Change in Quality of Life Following Liver Transplantation. *Quality of Life Research*, 9, 121-124.

O'Connor , N. and Tizard, J. (1956) *The Social Problem of Mental Deficiency*. Pergamon, London.

Oliver, C. and Holland, A. (1986) Down's Syndrome and Alzheimer's Disease: A Review. *Psychological Medicine*, 16, 307-322.

Orley, J. (1994) The World health Organisation (WHO) Quality of Life Project. In Trimble, M.R. and Dodson, W.E. (Eds.) *Epilepsy and Quality of Life*. Raven Press, New York.

Orley, J., Saxena, S. and Herrmann, H. (1998) Quality of Life and Mental Illness. *British Journal of Psychiatry*, 172, 291-293.

Osborne, S.P. (1992) The Quality Dimension: Evaluating Quality of Service and Quality of Life in Human Services. *British Journal of Social Work*, 22, 437-453.

Pearsall, J. and Trumble, B (Eds.) (1996) *The Oxford English Reference Dictionary*. (2nd Edition) Oxford University Press, Oxford.

Perry, J. and Felce, D. (1994) Outcomes of Ordinary Housing Services in Wales: Objective Indicators. *Mental Handicap Research*, 7, 286-311.

Perry, J. and Felce, D. (1995) Measure for Measure: How do Measures of Quality of Life Compare? *British Journal of Learning Disabilities*, 23, 134-137.

Pibernik-Okanović, M., Szabo, S. and Metelko, Ž. (1996) Quality of Life in Diabetic, Otherwise Ill and Healthy Persons. *Diabetologia Croatia*, 23, 117-121.

Power, M. Bullinger, M. and Harper, A. (1999) The World Health Organisation WHOQOL-100: Tests of the Universality of Quality of Life in 15 Different Cultural Groups Worldwide. *Health Psychology*, 18, 495-505.

Pratt, M.W., Luszcz, M.A. and Brown, M.E. (1980) Measuring Dimensions of the Quality of Care in Small Community Residences. *American Journal of Mental Deficiency*, 85, 188-194.

Prince, P.N. and Prince, C.R. (2001) Subjective Quality of Life in the Evaluation of Programs for people with Serious and Persistent Mental Illness. *Clinical Psychology Review*, 21, 1005-1036.

Raphael, D. (1996) Defining Quality of Life: Eleven Debates Concerning Its Measurement. In Renwick, R, Brown, I. and Nagler, M. (Eds.) *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues and Applications*. Sage Publications, Thousand Oaks.

Rapley, M. and Antaki, C. (1996) A Conversation Analysis of the 'Acquiescence' of People with Learning Disabilities. *Journal of Community and Applied Social Psychology*, 6, 207-227.

Rapley, M. and Lobley, J. (1995) Factor Analysis of the Schalock and Keith (1993) Quality of Life Questionnaire: A Replication. *Mental Handicap Research*, 8, 194-202.

Rapley, M., Ridgeway, J. and Beyer, S. (1997) Staff:Staff and Staff:Client Reliability of the Schalock and Keith (1993) Quality of Life Questionnaire. *Journal of Intellectual Disability Research*, 42, 37-42.

Rawlings, S. A. (1985) Life-styles of Severely Retarded Non-communicating Adults in Hospitals and Small Residential Homes. *British Journal of Social Work*, 15, 281-293.

Rawlings, S. (1985) Behaviour and Skills of Severely Retarded Adults in Hospitals and Small Residential Homes. *British Journal of Psychiatry*, 146, 358-366.

Reinders, J.S. (2002) The Good Life for Citizens with Intellectual Disability. *Journal of Intellectual Disability Research*, 46, 1-5.

Renwick, R. and Brown, I. (1996) The Centre for Health promotions Conceptual Approach to Quality of Life: Being, Belonging and Becoming. In Renwick, R, Brown, I. and Nagler, M. (Eds.) *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues and Applications*. Sage Publications, Thousand Oaks.

Rescher, N. (1972) *Welfare: Social Issues in Philosophical Perspective*. University of Pittsburg Press, Pittsburg.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Turner, S., Kessissoglou, S. and Hallam, A. (2000) Lifestyle Related Risk Factors for Poor Health in Residential Settings for People with Intellectual Disabilities. *Research in Developmental Disabilities*, 21, 469-486.

Robertson, J., Emerson, E., Hatton, C., Gregory, N., Kessissoglou, S., Hallam, A. and Noonan Walsh, P. (2001) Environmental Opportunities and Supports for Exercising Self-Determination in Community based Residential Settings. *Research in Developmental Disabilities*, 22, 487-502.

Robson, C (1993*) Real World Research: A Resource Book for Social Scientists and Practitioner-Researchers*. Blackwell, Oxford.

Rooney, K. (Ed.) (1999) *Encarta World English Dictionary*. Bloomsbury, London.

Sandhu, S. (1996) *'What I Would Like in My Life': Valued Attributes for People with a Learning Disability*. PhD Thesis, University of Birmingham, Birmingham. Cited in Hensel, E., Rose, J., Sternfert-Kroese, B. and Banks-Smith, J. (2002) Subjective Judgements of Quality of Life: A Comparison Study Between People with Intellectual Disability and Those without Disability. *Journal of Intellectual Disability Research*, 46, 95-107.

Sartorius, N. and Kuyken, W. (1994) Translation of Health Status Instruments. In Orley, J. and Kuyken, W. (Eds.) *Quality of Life Assessment: International Perspectives*. Springer-Verlag, Berlin.

Saxby, H., Thomas, M. Felce, D. and de Kock, U. (1986) The Use of Shops, Cafes and Public Houses by Severely and Profoundly Mentally Handicapped Adults. *British Journal of Mental Subnormality*, 32, 69-81.

Saxena, S. and Orley, J. (1997) Quality of Life Assessment: the World Health Organisation Perspective. *European Psychiatry*, 12 (Suppl 3) 263-266.

Schalock, R.L. (1994) Quality of Life, Quality Enhancement and Quality Assurance: Implications for Program Planning and Evaluation in the Field of Mental Retardation and Developmental Disabilities. *Evaluation and Program Planning*, 17, 121-131.

Schalock, R.L. (1997) The Conceptualisation and Measurement of Quality of Life: Current Status and Future Considerations. *Journal on Developmental Disabilities*, 5, 1-21.

Schalock, R.L. (2004) The Concept of Quality of Life: What We Know and Do Not Know. *Journal of Intellectual Disability Research*, 48, 203-216.

Schalock, R.L., Keith, K.D., Hoffman, K. and Karan, O.C. (1989) Quality of Life: Its Measurement and Use. *Mental Retardation*, 27, 25-31.

Schalock, R.L. and keith, K.D. (1993) *Quality of Life Questionnaire*. IDS Publishers, Worthington, Ohio.

Schipper, H., Clinch, J.J. and Olweny, C.L.M. (1996) Quality of Life Studies: Definitions and Conceptual Issues. In Spilker, B. (Ed.) *Quality of Life and Pharmacoeconomics in Clinical Trials* (2nd Edition). Lippincott-Raven, Philadelphia.

Schwartz, C. and Rabinovitz, S. (2003) Life Satisfaction of People with Intellectual Disability Living in Community Residences: Perceptions of the Residents, Their Parents and Staff Members. *Journal of Intellectual Disability Research*, 47, 75-84.

Scottish Executive (2000) *The Same as You? A Review of Services for People with Learning Disabilities*. HMSO, Edinburgh.

Scottish Executive (2004) *Home at Last? Report of a Short Life Working Group on Hospital Closure and Service Reprovision*. HMSO, Edinburgh.

Scottish Home and Health Department (1992) *The Future of Mental Handicap Hospital Services in Scotland*. HMSO, Edinburgh.

Scottish Home and Health Department and Scottish Education Department (1972) *Services for the Mentally Handicapped*. Scottish Office, Edinburgh.

Scottish Home and Health Department and Scottish Education Department (1979) *A Better Life: Report on Services for the Mentally Handicapped in Scotland.* HMSO, Edinburgh.

Shiell, A., Pettifer, C., Raynes, N. and Wright, K. (1992) The Costs of Community Residential Facilities for Adults with a Mental Handicap in England. Mental Handicap Research, 5, 115-129.

Sigelman, C.K. and Budd, C.E. (1986) Pictures as an Aid in Questioning Mentally Retarded Persons. *Rehabilitation Counselling Bulletin*, March, 173-181

Sigelman, C.K., Budd, C.E., Spanhel, C.L. and Schoenrock, C.J. (1981) When in Doubt Say Yes: Acquiescence in Interviews with Mentally Retarded Persons. *Mental Retardation*, 53-58.

Sinson, J. (1990) Micro-institutionalisation? Environmental and Managerial Influences in Ten Living Units for People with mental Handicap. *British Journal of Mental Subnormality*, 36, 77-86.

Skevington, S. M. (1994) Social Comparisons in Cross-Cultural Quality of Life Assessment. *International Journal of Mental Health*, 23, 29-47.

Skevington, S. M. (1998) Investigating the Relationship between Pain and Discomfort and Quality of Life, Using the WHOQOL. *Pain*, 76, 395-406.

Skevington, S. (1999) Measuring Quality of Life in Britain: Introducing the WHOQOL-100. *Journal of Psychosomatic Research*, 47, 449-459.

Skevington, S., Bradshaw, J. and Saxena, S. (1999) Selecting National Items for the WHOQOL: Conceptual and Psychometric Considerations. *Social Science and Medicine*, 48, 473-487.

Skevington, S., MacArthur, P. and Somerset, M. (1997) Developing Items for the WHOQOL: An Investigation of Contemporary Beliefs about Quality of Life Related to Health in Britain. *British Journal of Health Psychology*, 2, 55-72.

Skevington, S. and Tucker, C. (1999) Designing Response Scales for Cross-Cultural Use in Health Care: Data from the Development of the UK WHOQOL. *British Journal of Medical Psychology,* 72, 51-61.

Smith, A. (2000) *Researching Quality of Life of Older People: Concepts, Measures and Findings*. Centre for Social Gerontology, Keele University, Staffordshire.

Spilker, B. (1996) Introduction. In Spilker, B. (Ed.) *Quality of Life and Pharmacoeconomics in Clinical Trials* (2nd Edition). Lippincott-Raven, Philadelphia.

Stancliffe, R.J. (2001) Living with Support in the Community: Predictors of Choice and Self-Determination. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 91-98.

Stancliffe, R.J. and Keane, S. (2000) Outcomes and Costs of Community Living: A Matched Comparison of Group Homes and Semi-Independent Living. *Journal of Intellectual and Developmental Disability*, 25, 281-305.

Stanley, B. and Roy, A. (1988) Evaluating the Quality of Life of People with Mental Handicaps: A Social Validation Study. *Mental Handicap Research*, 1, 197-210.

Szabo, S. (1996) The World Health Organisation Quality of Life (WHOQOL) Assessment Instrument. In Spilker, B. (Ed.) *Quality of Life and Pharmacoeconomics in Clinical Trials* (2nd Edition). Lippincott-Raven, Philadelphia.

Szabo, S., Orley, J. and Saxena, S. (1997) An Approach to Response Scale Development for Cross-Cultural Questionnaires. *European Psychologist*, 2, 270-276.

Tabachnick, B.G. and Fidell, L.S. (1996) *Using Multivariate Statistics* (3rd Edition) Harper Collins, New York.

Tazaki, M., Nakane, Y., Endo, T., Kakikawa, F., Kano, K., Kawano, H., Kuriyama, K., Kuroko, K., Miyaoka, E., Ohta, H., Okamoto, N., Shiratori, S., Takamiya, S., Tanemura, K. and Tsuchiya, R. (1998) Results of a Qualitative and Field Study using the WHOQOL Instrument for cancer Patients. *Japanese Journal of Clinical Oncology*, 28, 134-141.

Thiele, R.L., Paul, J.L. and Neufeld, G.R. (1977) Institutionalisation: A Perspective for De-institutionalisation Program Development. In Paul, J.L, Stedman, D.J. and Neufeld, G.R. (Eds.) *De-institutionalisation.* Syracuse University Press, New York.

Thomas, M., Felce, D., de Kock, U., Saxby, H. and Repp, A. (1986) The Activity of Staff and of Severely and Profoundly Mentally Handicapped Adults in Residential Settings of Different Sizes. *British Journal of Mental Subnormality*, 32, 82-92.

Tizard, J. (1964) *Community Services for the Mentally Handicapped.* Oxford University Press, London.

Tizard, J. and O'Connor, N. (1952) The Occupational Adaptation of High-grade Defectives. *The Lancet*, 2, 620.

Verri, A., Cummins, R.A., Petito, F., Vallero, E., Monteath, S., Gerosa, E. and Nappi, G. (1999) An Italian-Australian Comparison of Quality of Life Among People with Intellectual Disability Living in the Community. *Journal of Intellectual Disability Research*, 43, 513-522.

Vreeke, G.J., Janssen, C.G.C., Resnick, S. and Stolk, J. (1997) The Quality of Life of People with Mental Retardation: In Search of an Adequate Approach. *International Journal of Rehabilitation Research* 20, 289-301

Walker, C., Ryan, T and Walker, A. (1993) *Quality of Life after Resettlement for People with Learning Disabilities: Summary of the Report to the North West Regional Health Authority.* Department of Sociological Studies, Sheffield.

Ware, J. E. and Sherbourne, C. D. (1992) The MOS 36-Item Short Form Health Survey (SF-36) I: Conceptual Framework and Item Selection. *Medical Care*, 30, 473-483.

Ware, J. E. (1996) The SF-36 Health Survey. In Spilker, B. (Ed.) *Quality of Life and Pharmacoeconomics in Clinical Trials* (2nd Edition). Lippincott-Raven, Philadelphia.

Welsh Office (1978) NIMROD: *Report of a Joint Working Party on the Provision of a Community Based Mental Handicap Service in South Glamorgan.* Welsh Office, Cardiff.

Welsh Office (1982) *Report of the All Wales Working Party on Services for Mentally Handicapped People.* Welsh Office, Cardiff.

Welsh Office (1983) *All Wales Strategy for the Development of Services for Mentally Handicapped People.* Welsh Office, Cardiff.

WHOQOL Group (1993a) WHOQOL *Focus Group Work.* WHO, Geneva.

WHOQOL Group (1993b) Study Protocol for the World Health Organisation Project to Develop a Quality of Life Assessment Instrument (WHOQOL). *Quality of Life Research*, 2, 153-159.

WHOQOL Group (1994a) The Development of the World Health Organisation Quality of Life Assessment (the WHOQOL) In Orley, J. and Kuyken, W. (Eds.) *Quality of Life Assessment: International Perspectives.* Springer-Verlag,Berlin.

WHOQOL Group (1994b) Development of the WHOQOL: Rationale and Current Status. *International Journal of Mental Health*, 23, 24-56.

WHOQOL Group (1995) The World Health Organisation Quality of Life Assessment (WHOQOL): Position Paper from the World Health Organisation. *Social Science and Medicine*, 41, 1403-1409.

WHOQOL Group (1996) *WHOQOL-BREF Field Trial Version*, WHO, Geneva.

WHOQOL Group (1998a) Development of the World Health Organisation WHOQOL-BREF Quality of Life Assessment. *Journal of Psychological Medicine*, 28, 551-558.

WHOQOL Group (1998b) The World health Organisation Quality of Life Assessment (WHOQOL): Development and General Psychometric Properties. *Social Science and Medicine*, 46, 1569-1585.

Wilson, D. and Haire, A. (1990) Health Screening for People with Mental Handicap Living in the Community. *British Medical Journal*, 301, 1379-1380.

Wing, L. (1989) Hospital Closure and the Resettlement of Residents – The Case of Darenth Park. Gower, Aldershot.

Wirnsberger, R.M., De Vries, J., Jansen, T.L.Th.A., Van Heck, G.L., Wouters, E.F.M. and Drent, M. (1999) Impairment of Quality of Life: Rheumatoid Arthritis Versus Sarcoidosis. *The Netherlands Journal of Medicine*, 54, 86-95.

Wolfensberger, W. (1972) *Normalisation: The Principle of Normalisation in Human Services.* National Institute on Mental Retardation, Toronto.

Wolfensberger, W. (1983) Social Role Valorisation: A Proposed New Term for the Principle of Normalisation. *Mental Retardation* 21, 234-239

World Health Organisation (1998) *Draft WHOQOL User Manual.* WHO, Geneva.

Yeates, S. (1995) The Incidence and Importance of Hearing Loss in People with Severe Learning Disability: The Evolution of a Service. *British Journal of Learning Disabilities*, 23, 79-84.

Young, L. and Ashman, A.F. (2004a) De-institutionalisation in Australia Part I: Historical Perspective. *British Journal of Developmental Disabilities*, 50, 21-28.

Young, L. and Ashman, A.F. (2004b) De-institutionalisation in Australia Part II: Results from a Long-Term Study. *British Journal of Developmental Disabilities*, 50, 29-45.